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An Exploration of Lay Epidemiology and Cancer

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Thesis submitted for the degree of Doctor of Philosophy

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Abstract

Some estimates suggest that as much as 70% of cancer is preventable by disease modification alone (Peto 1991). Disease prevention via behavioural change is a challenging endeavour. There is widespread recognition that for behaviour to be better understood there is a need to understand the context in which it occurs, and the beliefs that underpin it. Lay epidemiology illustrates the sophistication of belief formation. The arrival at a coronary candidate provides according to Davison, Frankel and Davey Smith (1991), a cultural mechanism that aids the estimation of risk as observed from known cases in the family and wider society. Consequently, the estimate provides the potential motivation for behavioural choices. Other studies that followed the original model of lay epidemiology have similarly described the coronary candidate (Preston 1997; Emslie, Hunt & Watt 2001a; Frich, Malterud & Fugelli 2007; Weiner 2009) and suggest that the lay public have an understanding of the risk profile for Coronary Heart Disease.

This study aimed to explore the utility of the elements held within lay epidemiology in cancer beliefs. Do the lay public recognise a 'cancer candidate'?

Method: A series of 31 in-depth semi-structured interviews were conducted between November 2007 and October 2008. Interviews took place in two communities in Glasgow, Scotland - one affluent, one deprived. The sample was drawn from a number of community organisations and leisure clubs in the communities to facilitate accessing an 'ordinary' view. Cancer sufferers were excluded from the study. A topic guide was used to ensure consistency throughout interviews and focused on participants' experience of cancer. Although the study did not adhere to a strict grounded theory approach, the analytic method of constant comparative analysis was followed.

Findings: The complexity of the scheme described by Davison, where a wide range of sources of knowledge to inform beliefs resonated. Sophisticated and complex explanatory models of cancer were described. Cancer inhabited an important cultural position and was most commonly associated with fear and dread. Possible aetiological explanations included behavioural, environmental, biological and psychological factors. Smoking was the most widely recognised risk factor. Knowledge of other risk factors for individual cancers was patchy.

Candidacy therefore was not as unequivocal for cancer. Many 'anomalous cases' (those without obvious explanation) were proffered. Ultimately the randomness of cancer was emphasised.

Conclusion: Cancer is a more complex disease than CHD, both culturally and biomedically and this is reflected in the beliefs voiced by participants in this study. This complexity is a barrier to the adoption of a cancer candidate.

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Declaration of authorship

All of the work reported in this thesis was designed, conducted, analysed and written up by the author.

The following presentations have been made based on material contained in this thesis:

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‘An exploration of Lay Epidemiology and cancer’. British Sociological Association: Medical Sociology Annual Conference, Manchester, UK. September 2009.

Definitions

The following abbreviations are used throughout the thesis:

BMI	Body Mass Index
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CHD	Coronary Heart Disease
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1. Introduction & Background

When Geoffrey Rose (1985) stated that everyone 'is a high risk individual for this mass disease', he was referring to Cardiovascular Disease. This could equally apply to cancer early in the 21st Century. The latest World Health Organisation figures show that cancer continues to represent a considerable global disease burden. Each year 12 million new cancers are diagnosed and 7.9 million people die of the disease, representing a total of one in every eight worldwide deaths¹. Current estimates suggest that three in five of the UK population will suffer from some form of cancer over their lifetime and in Scotland 15,000 people die of cancer each year. Despite a number of reviews of cancer care since the publication of the Calman-Hine report in 1995, the overarching policy objectives have remained unchanged; a reduction in incidence and an improvement in survival. Survival has improved significantly as a result of improvements in early detection and the enhancement of existing cancer services. More of a challenge to policy is a reduction in incidence, which requires primary prevention via behavioural change, arguably cancer's holy-grail. Together environment and behaviour account for 90-95% of all cancers and estimates suggest that 70% of cancer is preventable through behavioural modification alone (Peto 2001).

In Scotland though the overall incidence of cancer in men reduced by 4% in 2008, it rose in women in equal part during the same period². Most of the improvement in incidence among males is the result of the reductions in lung cancer. Incidence in other sites is however rising, as is lung cancer in women. Gender is not the only social determinant of cancer status. Cancer incidence and mortality is greater and survival is poorer among the most deprived across industrialised countries (Coleman et al 2004; Faggiano et al 1997; Shack et al 2007). Although survival is closely associated with stage at presentation, evidence that those from deprived communities present with more advanced disease is inconsistent (Brewster et al 2001). Social patterns are perhaps unsurprisingly apparent in behaviour as well as incidence and survival. Across a range of measures, those in the least affluent communities are more likely to engage in the unhealthy behaviours associated with cancer. An estimated 10 million people over 16 in the

¹ <http://www.who.int/cancer/> accessed 26/10/10

² <http://www.isdscotland.org/isd/183.html>

UK smoke regularly. On average 22% of men smoke in the UK. When this figure is broken down it shows that 16% of men in the most affluent communities smoke compared to 27% of in the least affluent³. Scotland has higher than average smoking rates when compared to the rest of the UK, though this has reduced from 29% in 1999 to 25% in 2008. However smoking in areas of deprivation is consistently higher than elsewhere, with 42% of current smokers living in the 15% of most deprived areas⁴. The numbers of those classed as obese in Scotland has been steadily rising since 1995. Obesity, once the preserve of the wealthy, is now associated with deprivation. As deprivation increases so does obesity, and the trend is particularly strong among women⁵. Related to this, consumption of fruit and vegetables is 1.5 times higher among affluent groups (James et al 1997). It would appear that those in deprived communities are most resistant to life-style change and the adoption of healthy behaviours. Moreover, research shows that cancer risk behaviours are adopted and established at a relatively young age. Those from more deprived communities were more likely to have tried smoking, to eat a high fat diet and be overweight (Wardle et al 2003).

1.1 Promoting Health

All of this risky behaviour occurs in a climate where more and more information about health and healthy behaviours is available. The dominant policy discourse is now firmly in the realm of individual responsibility (Davison & Davey Smith 1995) and closely follows the biomedical model. Health promotion urges individuals to 'choose' healthy living and healthy lifestyles. The assumption is that awareness and knowledge provide the basis for that choice. Individuals are aware of healthy and unhealthy behaviours and many, particularly those in the most deprived communities, simply make the 'wrong' choice. This is often assumed to be both irrational and fatalistic (Balshem 1991) because a linear causal relationship between knowledge and behaviour is expected.

Many psychological theories have been developed that aim to explain behaviour and ultimately facilitate behavioural change. Wallaston (1976) developed the

³ <http://info.cancerresearchuk.org/cancerstats/types/lung/smoking/#cancer> accessed 26/10/10

⁴ <http://info.cancerresearchuk.org/cancerstats/types/lung/smoking/#cancer> accessed 26/10/10

⁵ <http://www.scotpho.org.uk/nmsruntime/saveasdialog.asp?IID=4048&SID=3489> accessed 26/10/10

Health Locus of Control concept which proposed that those who felt most in control of their own health are more likely to take steps to change their behaviour. The hypothesis follows that encouraging individuals to augment their sense of control will result in the adoption of healthier behaviours. Although two large studies (Friis et al 2003; Steptoe and Wardle 2001) found that high levels of internal control were predictors of 'good' behaviour, findings on the whole have been inconsistent (Lyons & Chamberlain 2006). Bandurra (1977) introduced the notion of self-efficacy into predictive models and focused on an individual's perception of ability and achievement. In short, behavioural change is more likely to be achieved if there is an inherent belief that the outcome will be positive and that it is within the realms of capability. To stop smoking an individual must not only want to but also believe that they are able to do it. Self-efficacy is also integral to Ajzen's (1991) Theory of Planned Behaviour. The Theory of Planned Behaviour developed from the Theory of Reasoned Action, which had intention at its heart but took cognisance of social norms and attitudes. It has been widely used in health research (Armitage & Conner 2001; Webb & Sheeran 2006) and is a well supported concept, though Stainton-Rogers (1991) criticised the model for being trivial. Attitudes and behaviours are also vital to the Health Belief Model. It introduces the idea of personal susceptibility to disease, perceived disease severity and the consequences of engaging in the behaviour. It also looks specifically at the presence of triggers or cues to action. Holm and colleagues (1999) found strong associations between those who attended for mammography and the belief that cancer screening was a worthwhile activity but it has been thought to be weak in predicting behaviour (McCord 1997; Lyons & Chamberlain 2006). In addressing the criticism that such models are static, Prochaska and Di Clemente (1983) introduce stage models which accept that beliefs will change during the lifecourse and offer a circular rather than linear approach. All of these models have met with criticism, generally for being too simplistic (Ogden 2008). Stainton-Rogers (1991) argued that behaviours do not occur in such a formulaic manner, but more importantly the theories fail to consider the social context.

1.2 Incorporating the social

Although social measures, like sanitation and housing, were known to have clear health benefits and succeeded in improving the nation's health, it is medicine

that has dominated the public health agenda. Yet, the validity of its dominance has been questioned, especially since biomedicine fails to explain social patterns in the experience and causes of ill health (Calnan 1987). This is not the only criticism levelled at biomedicine. Much of medical sociology, from functionalism (Parsons 1951) to critical theorists (Illich 1976; Navarro 1977), has examined the role of medicine in the everyday lives of the individual and, ultimately both draw distinctions between the ‘professional’ and the ‘patient’. Though it now seems rather old-fashioned not to consider the lay perspective it has not always been widely accepted that understanding lay views about health can add much to the understanding of lay beliefs and behaviour (Friedson 1970). Popay and Williams (1996) go as far as to suggest that ignoring the lay voice is foolhardy, particularly as it can offer untold insights into the experience of health and illness.

Shaw (2002) however urged caution when dealing with the lay voice and questions how ‘lay’ such voices really are. Shaw took what he called ‘the Helsinki study’ (Kangas 2001), which looked at illness narratives of depressed patients, as his starting point, and asked if anyone in modern society can be truly ‘lay’. He suggested that the distinction between ‘lay’ and ‘expert’ has outgrown its usefulness. He cited many examples of research that demonstrated that when looking for meaning about illness, patients in reality often adopt professional explanations. Moreover, policy explicitly encourages the ‘expert patient’ (Department of Health 2001). Shaw quoted Kangas’ study, which despite referring to depression in this instance could equally apply across the illness spectrum:

“Lay perceptions of depression are made of bits and pieces taken from many sources, reflecting the fact that individual, social and cultural contextualization of depression takes place in an era of increasing reflexive practices . . . Lay theories, perceptions and explanations. . . are constructed and negotiated in an increasingly plural and complex environment of knowledge”. (Kangas, 2001: 89 cited in Shaw (2002))

This complexity does not suggest that ‘lay’ experiences should not be explored. Rather Shaw suggested that any exploration be mindful of the growing overlap between lay and expert knowledge and be sceptical of claims that the two inhabit entirely different spheres.

The similarities between the 'lay' and expert positions are highlighted by Davison and colleagues' work on lay epidemiology (Davison, Frankel and Davey Smith 1991). The lay epidemiology model suggests the lay public draws on knowledge and experience to develop a sophisticated system of beliefs that, while mindful of health education messages, are set within the context of experience and, are evidence based. This evidence may be gathered from family, community, or societal events and each event will impact on beliefs to varying degrees. The model offered an insight into why some individuals may be resistant to change behaviours that may make them susceptible to, in this instance coronary heart disease (CHD). Could the model be of equal value when considering other diseases, particularly those that are strongly associated with known risk factors and countless health promotion efforts?

This thesis aims to explore the utility of the lay epidemiology model in the context of cancer beliefs. The thesis has four main sections. The beginning section concentrates on the literature, by first reviewing studies of health beliefs from which lay epidemiology is drawn, before going on to outline lay epidemiology more closely. The second part of the literature review takes cancer as its focus and looks not only at general cancer awareness but also more broadly at the cultural position of cancer in our society. This first sections ends with a number of questions that the study sought to answer. The second shorter section turns to methods, and in two chapters, outlines the broader methodological considerations of the study before going on to detail the research design and process. The data findings are then presented in four chapters. Chapter 7 introduces the sample, before going on to describe the participants experience of cancer in Chapter 8. The meaning and understanding that participants' have derived from that experience is outlined in Chapter 9 and finally in Chapter 10 the findings are explored in the context of lay epidemiology. Throughout the data findings chapters other relevant research is considered and included. The final sections in Chapters 11 and 12 discuss the findings, in light of the research questions, summarise the study and reach some conclusions about the usefulness of the lay epidemiology model when exploring cancer beliefs.

2. Literature Review

2.1 Literature Review Introduction

This literature review has three aims. First, it aims to provide a context for the thesis by outlining the wider literature on health beliefs. Next, to explore thoroughly the concept of lay epidemiology, and finally, to detail what is known about cancer among the lay population. The literature review will be separated into two chapters. The first will focus on health beliefs, including lay epidemiology, and the second on cancer.

Both ‘health beliefs’ and ‘cancer’ are represented by large literatures. It would be impossible to present either in their entirety, and so it is important to outline what literature will be reflected on in the following chapters.

2.1.1 What literature is included?

Tackling subjects with potentially limitless amounts of research means that setting early parameters is crucial. Studies of the lay experience of health have a long and varied history and have changed the way in which we think about the illness experience (Lawton 2003). Those that centre on the health beliefs of ‘lay’ public are less common. Early studies that simply teased out definitions have now given rise to a wealth of literature that considers beliefs among various social, demographic and ethnographic groupings. Such studies have further developed to describe and interpret the beliefs of various disease-specific constituencies. Despite such variety the majority of this work has its origins in a number of key health belief texts. Their inclusion in this thesis is based on the acknowledgement that these works are important forerunners of much of the health belief literature that has followed.

Hughner and Kleine (2004) recently conducted a review of health beliefs literature published between 1983 and 2003 and present a synthesis of the data from the 28 included studies. Many of the studies included are dealt with in detail within this chapter because of their significance in the field of study. Hughner and Kleine present 18 different health themes that they then combined to give four key areas. These concentrate on definitions, causal explanations,

external factors impinging on health, and the place of health in people's lives. They conclude that much of the work that has sought to define health has concentrated on illness rather than health. They also suggested that lay theories of health often do not match professional views, so for example lay groups value 'not lying down to' illness. People attribute responsibility for illness events to fate or luck and this is common throughout lay studies of health. Health too was judged to be taken for granted rather than something to be aimed for.

Like health beliefs, cancer and beliefs about cancer are represented by a wide literature. The area that is loosely termed psycho-oncology has looked closely at beliefs about cancer, but the focus has tended to be on cancer patients. The extent to which such studies truly access the 'lay' voice is questionable. As Shaw (2002) asserts, patients become, over the course of their illness, experts. In addition, there are numerous studies that explore very specific aspects of cancer beliefs, for example beliefs about screening, or symptom awareness. The literature reviewed here will therefore be confined to studies relating to beliefs about cancer among the lay public. Unless especially relevant, the views of patients and their carers will not be reviewed.

2.1.2 Search Strategy

Each element of this review required its own discrete literature search. Medical sociology readers were used as the starting point to locate important health beliefs texts. Citation searches were widely used and frequently cited texts were considered. By focusing solely on lay epidemiology, the thesis has an arguably narrow remit, which negates the conventional approach to literature searching that values 'inclusivity'. Besides, a search for the term 'lay epidemiology, yields little. Again, citation searches addressed this gap. A more traditional approach to searching was adopted for the cancer beliefs element of the review. Electronic databases including MEDLINE, CINAHL and Web of Knowledge were searched using the terms cancer*, know*, aware*, belief*, lay and public. The main inclusion criteria were studies that considered beliefs about cancer among non-patients and studies that focused on cancer generally. Those studies that primarily considered awareness and beliefs about screening were not included.

The remainder of this chapter will deal with health beliefs. It will first introduce a number of seminal texts that provide the historical and theoretical background for lay epidemiology before going on to give an in-depth account of lay epidemiology.

2.2 The theoretical context: unearthing beliefs about health.

Many of the early studies that introduced lay beliefs about health are to be found in social anthropology. The first ethnographies are attributed to Rivers (1924) and later Clements (1932) and Ackerknecht (1942). These analyses tended to describe health beliefs in non-western cultures. They focused on irrational ‘primitive’ beliefs and are now considered to be, at best, patronising. The paternalistic offerings from social anthropology soon gave way to less disparaging ‘systems theories’, which proposed that views about health mirrored overall cultural belief systems (Dunn 1968). The dominance of the biomedical model has meant that similar analyses of western health beliefs were largely absent. The assumption being that scientific explanations obviate the need to explore lay beliefs of health. As such, the lay voice was almost entirely neglected. Lupton (1994) traced the history of lay beliefs and noted that many of the early offerings relied heavily on professional/scientific accounts. She suggested that the shift from pre-Enlightenment beliefs about health and disease, where religion and morality were integral, to the scientific post-Enlightenment model rendered lay beliefs meaningless. The body became viewed as a series of mechanistic parts that could be treated and cured in isolation. This marked the beginning of biomedicine’s hegemony. A further 300 years passed before the gaze began to readjust to incorporate non-scientific models.

2.2.1 *Lay beliefs*

As has already been detailed, studies that consider lay beliefs about health have borrowed heavily from social anthropology. The emphasis on the ‘otherness’ apparent in beliefs about health in non-Western or ‘primitive’ societies has spilled into studies of lay views in contemporary western societies. As Bury (1997) highlights, a tension arises when it is assumed that ‘expert’ views are

‘correct’ and lay ‘beliefs’ are inherently ‘wrong’. In this context terminology becomes important, for example early labelling of beliefs as ‘folk’ tended to emphasise the discord between lay and professional viewpoints. The contention being that ‘belief’ is secondary to ‘knowledge’. Irrespective of the semantics it is clear that much can be gained from giving the ‘lay’ perspective recognition. Popay and Williams (1996) argued that the recognition of lay knowledge can be advantageous in many ways. First, they cite Hilary Graham’s (1987) influential work on smoking patterns among young women living in areas of social disadvantage that highlighted the importance of understanding health behaviour in the context of peoples’ lives. They also demonstrated that there have been instances where lay knowledge has prompted the scientific community to reassess their knowledge. Links between poor health and environmental factors, housing conditions and work hazards are all given as examples of occasions where lay knowledge informed scientific knowledge rather than vice versa. Despite their pleas for parity between lay and scientific knowledge, Popay and Williams equally stressed their inherent differentness:

“For the most part, however sophisticated and sociologically illuminating the knowledge expressed in lay beliefs may be, it remains disorganised and ad hoc, posing little if any direct challenge to the medical profession. However much these beliefs are part of a shared culture and society, they are expressions of personal experiences which remain outside the world of science and politics”. (Popay and Williams pg 118 cited in Challenging medicine Gabe (ed))

It is this spirit that is evoked in this thesis. Using the term lay beliefs throughout should not detract from their value.

2.2.2 Describing lay beliefs.

Lay beliefs are now widely researched. Data that allow better understanding of the health beliefs of various socio-cultural groups are widely available, as are narrowly focused disease specific areas. It is a vast literature. Yet, while new insights are offered into the nuances of belief, the majority of current lay beliefs work owes much to a number of early, seminal studies. The following section details a series of important qualitative health belief studies. While they have been instrumental in improving an understanding of many aspects of health

beliefs, they have been included here because they say something about lay notions of causality, or lay aetiology, which is central to lay epidemiology.

Claudine Herzlich's (1973) work concentrated on the social representations of health. She carried out a study of health beliefs among 80 middle-class individuals, most living in Paris but also some in Normandy. Herzlich believed that the views expressed by her respondents demonstrated that their thoughts on health were quite distinct from those of professionals. Her findings show that health was judged in three different but often overlapping ways. First, health as a 'vacuum' wherein health is essentially seen as the absence of disease that only becomes apparent during periods of illness. Second, health as a 'reserve', where health is inherent but can be added to or augmented and ultimately used to fight illness. Finally, 'equilibrium', described as a higher state of ideal health that is threatened by ways of life. She questioned her respondents about where health 'came from'. Respondents placed health in two separate categories; the endogenous, or that which could be found inside an individual and the exogenous, found outside the individual. Yet it was the exogenous, represented as the 'way of life' that posed the greatest threat to health. City-living, and living in Paris in particular, exposed its inhabitants to a series of health threats borne out of the fast pace of life, pollution, germs and modernity in general. The impact on health was both physical and emotional:

*"The constant commotion isn't made to make people ordinary, they are difficult, nervous, tired, that's the truth about modern life".
(Herzlich 1973 cited in Bury & Gabe 2004 pg28)*

Conversely country-dwellers were not subject to the same strains and as such had an altogether healthier way of life. City living meant many more opportunities to pass germs not so apparent in the country. The respondents identified three major diseases that were judged to be directly associated with modern life: cancer, mental ill health, and heart disease. These are the diseases which, according to Herzlich, were 'at the heart of individual preoccupations' and took on a 'special significance'. As one respondent said of cancer:

*"Cancer, I rather associate with current allergies, with very modern allergic diseases, with the physical and nervous strain we undergo in cities, and then in breathing in the present-day atmosphere in cities"
(Herzlich 1973 cited in Bury & Gabe 2004 pg29)*

Although there was recognition that the endogenous aspect of health contained inherent susceptibility to some diseases, a 'good' constitution could effectively guarantee health. Individuals were thought to possess protective traits. Herzlich captures the moral dimension integral to explanations of health. While illness is bad, health is good and health is to be found within the individual. Battle metaphors were utilised, suggesting that individuals are inherently strong and can fight the dangers associated with modern ways of life.

As noted earlier, part of the discourse in health beliefs has concerned itself with differences or indeed similarities between 'expert' and 'lay' views of health. Snow's (1974) study of health beliefs among Tucson residents demonstrated the dissimilarity of views between interviewees and biomedicine. Respondents' emphasis was on environmental and supernatural forces as the roots of disease and achieving 'balance' was seen as the key to good health. Snow's findings are interesting, yet they present 'illness' as a whole and do not draw distinctions between the aetiology of different illnesses or diseases. For example, there are no clear statements about causes of minor illnesses, like the common cold, although the inference is that voodoo or black magic may be reserved for more serious conditions. Conversely Helman's (1978) study that presents 'folk' models of belief among general practice patients in the UK shows similarities between doctor and patient accounts. Both groups draw distinctions between colds and fevers and their respective aetiologies. Like Snow, Helman found that the common cold was believed to be the result of environmental factors, like the weather. Fevers were thought to be the result of 'germs', a term borrowed from biomedicine. Helman concluded that biomedical concepts are easily integrated into 'folk' models and that doctors engage in collusion with patients to maintain the folk model. Both Helman and Snow's work offered interesting descriptions of beliefs but attempt neither to interpret nor explain them.

A more in-depth account is offered by Cornwell (1984) in her influential work in east London in the late 1970s. In an exploration of lay health beliefs among a working class community she highlighted the difference between 'public' and 'private' accounts of health and illness. Public accounts provide what the respondents believe are 'the right answers'. Cornwell suggested that the findings from her interviews show that in public accounts individuals tend to rely heavily on the medical model for explanation. This was less pronounced in

private accounts, which were more biographical and convoluted. According to Cornwell, her respondents presented causation of illness on three distinct, but interrelated, dimensions. First, illness was either internal or external, second, it was avoidable or unavoidable and finally an individual was either to blame or blameless in becoming ill. Despite illness being seen as avoidable, Cornwell noted respondents' reluctance to apportion blame. Yet, public accounts of health and illness were littered with moral judgements, particularly about attitudes to work and how effectively disease or illness was borne by individuals. Private accounts for Cornwell were more biographical in nature and often involved the retelling of narratives which held intricate causal explanations within them.

“The concept of the causal process was dynamic rather than static, with many factors interacting - acting and reacting upon each other - and with illness as the eventual outcome.” (Cornwell 198:149)

Respondents' reluctance to blame individuals for illness was coupled with scepticism about the relationship between behaviour and illness. For example, few respondents accepted the link between smoking and lung cancer. Most respondents knew individuals for whom smoking did not feature as a factor in their premature death or who had smoked and survived. Rather than lifestyle, individuals attracted blame when they were seen to dwell on problems, or failed to 'get on with life'. Overall the aim was to be seen as a survivor rather than a victim. Cornwell proposed that views about health were simply a feature of the wider belief system in the community or their 'hard -earned lives'.

Mildred Blaxter (1979, 1982, 1983, 1990) has been a prolific commentator on health beliefs. Blaxter (1979) Blaxter and Patterson (1982) and Blaxter (1983) presented findings from a study carried out with two generations of working class women in a Scottish city. The study demonstrated the wide-ranging and complex nature of aetiological theories. The study did not set out to look specifically at any particular aspect of health and illness, instead the women were asked to discuss issues about health and illness that were important to them. Blaxter noted:

Typically, these women had a very stoical, puritanical and at the same time fatalistic view of the occurrence of illness: illness was

weakness, 'lying down to it', being functionally unfit, giving in to diseases. (pg Blaxter 1983:60)

As with Cornwell's work, Blaxter uncovered the strength of the moral dimension inherent in thoughts about illness. Obviously health was seen as something positive and Blaxter believed that the respondents may have provided accounts that lessened the extent of illness in their lives. For both generations the most important response to illness was 'not lying down to it'. This cohort routinely described illness in what Blaxter called moral and spiritual, rather than physical, terms. The preoccupation with the moral dimension of health does have an important consequence. If some degree of ill health is inescapable, then the role of fatalism or 'bad luck' is augmented. The women in Blaxter's study mentioned a wide range of diseases, and a cause was ascribed to the most of those mentioned. The most common causes were infections, heredity, and family susceptibility, together with environmental factors such as living and working conditions. Blaxter noted that family susceptibility and heredity were given more credibility in lay theories than they are in medicine and the respondents supposed connections between disease patterns that were common in families. Other aetiological theories were based on the idea that stresses and strains, both physical and emotional, could 'bring on' disease. Many thought that disease could result in further disease, for example, a common cold could easily become pneumonia, if not carefully monitored. This is what Blaxter called a secondary event. Only with common diseases, like the cold or flu did Blaxter's respondents implicate individual behaviour as a cause of disease. Blaxter, like Cornwell, found that respondents were loath to incriminate individual behaviour. Often, respondents cited the natural constraints of poverty and the influence that this had on their own and their children's health. Yet, they were keen to stress that both rich and poor could be similarly afflicted by disease.

There are additional Scottish studies of health beliefs that have particular resonance here. Mullen's (1994) study of religion and health beliefs among middle-aged men in Glasgow found that many of his respondents thought that some diseases, like cancer, were 'in you' and were therefore fatalistic about one's ability to avoid them. Similarly 'constitutions' were marked out as important, though some thought it was possible to improve or bolster one's constitution. In an ethnographic study carried out with middle-class families in

Edinburgh, Backett (1992a 1992b) sought to explore beliefs about health and lifestyle in families that were in a strong position to be healthy; in terms of social and material advantage. Consistent with studies on health beliefs, Backett found that health was seen as multidimensional and that fate was included alongside scientific explanations. As Crawford (1984) established, Backett's families were eager to illustrate their good behaviours, and to demonstrate that they knew what healthy behaviour was. Yet, on closer consideration the imagined often did not match the reality. Few followed the healthy regimen that they thought was morally incumbent upon them. Thus, Backett concluded that with the increased amount of information available on health, awareness had changed but behaviour had not necessarily followed. Central to the discussions were ideas about balance, which was necessary for health, in all areas of life. Backett, Davison and Mullen (1994) brought together data from three separate studies that focused on health beliefs. They concluded that moderation, which is assumed vital for a healthy lifestyle, was the common feature across studies. There was a general resistance to a strict regime in any area of life and often participants talked about 'trading' good and bad behaviours.

In a further attempt to better understand beliefs about health, a series of studies by Pill and Stott (1982a, 1982b, 1985), asked a group of young mothers about the preventability of illness. They drew on the original concept of health locus of control (Wallaston 1976) to develop a tool that measured health behaviours. In terms of aetiology, a range of explanations were offered including heredity, personal susceptibility, environment, germs, lifestyle factors and personality. In the initial exploratory study approximately 20% of all informants denied any personal responsibility for health. Echoing other locus of control work, they found that informants could be separated into two key groups. 'Lifestylists, or those that saw individual responsibility for health, and 'fatalists' who believed that health and illness were largely out with the control of the individual. What was unique about their findings was that the two were not mutually exclusive:

"Most people appear to be quite capable of holding a number of apparently contradictory general theories of causation at the same time which are brought forward in various combinations depending on the situation and the nature of the questions asked". (Pill & Stott 1985:983)

Both lifestylists and fatalists believed that individuals had some responsibility for their own health but, while lifestylists believed this was the result of behavioural choice, fatalists understood this as the impact of worry, hypochondria, and dwelling on illness. Pill and Stott also found that views were socially patterned and those with even a marginally higher level of education were more likely to be 'lifestylists'.

Calnan's (1987) study considered the relationship between social class and health and compared the views of women in social class I and II with those in social class IV and V. Questions were about a series of health related beliefs and concepts, but of most relevance to this review are their beliefs about causality. Stress and obesity were key factors in the origin of CHD in both social class groups, and although other explanations like smoking and drinking were offered by both groups they prioritised them differently. Calnan reported that cancer stood out as the feared disease and that the 'logic in lay models was difficult to disentangle'. Cancer was attributed to a number of factors, and popular among middle class women were ideas of heredity and biological predisposition. He continued that these were distinct from ideas held by working class women, which he described in the following excerpt:

"The working-class women's accounts, while also characterised by doubt and uncertainty, identified a different type of theory about cancer causation to the one adopted by the middle class groups. The most popular theory adopted specifically by this group implied that cancer was in everybody or in some people and only needed to be triggered off." (Calnan 1987:65)

The impression that cancer is a dormant feature present in some or all of us is an interesting one. However, though Calnan was keen to make the distinction between the class groups, it might be argued that the ideas of predisposition and something 'in' everybody are essentially the same but articulated differently.

The review of these above provides a brief overview of some of the key texts in the origins of health belief literature. They show that individual beliefs about health are derived not only from experience but also from biomedical concepts that are incorporated easily into explanations. Though Herzlich suggested that the health beliefs of her interviewees were distinct from scientific explanations,

the evocation of the importance of germs is testimony to the salience of biomedicine. Herlizch's idea of health as a 'reserve' is common in many of the reviewed studies. For many, health is an inherent abstract concept that is thought about only in response to a specific health-related problem. It is only in these circumstances that thoughts turn to health and illness and the search for explanation begins. Ascertaining the reasons for poor health or illness events and the extent to which the sufferer is to blame are arrived at in response to the event. Common in the studies is the notion of naturally occurring differences, or inherent constitutions, between individuals. Illnesses too have inherent differences. Participants across studies categorise illness into those that can be avoided and those that cannot. A constant seam runs through the studies that highlight the moral expectations placed on the ill, who must not 'lie down' to illness. Yet parallel to this the studies also report a reluctance to apportion blame to individual disease sufferers (unless the disease was thought avoidable). Although these studies are now historical they do show that lay views are complex and sophisticated. They perhaps reflect the context in which they were undertaken. For many of those interviewed illness primarily meant infection. The studies took place in an era before the, now dominant, narrative relating to prevention took hold. The avoidance of illness via abstention from risky behaviour now places the responsibility firmly with the individual.

2.2.3 Explaining Health Beliefs

While the reviewed studies are illuminating they do not aid our understanding of the process involved in constructing beliefs. Kleinman (1980) describes what he terms explanatory models, which are activated during episodes of individual illness. Crucially these are separate from generic beliefs that are ever-present. Explanatory models allow individuals to account for, and make sense of, poor health by giving details of what they might expect to happen within one illness episode. These expectations are culturally created and allow individuals to share experiences, so for example the experience of the common cold is well-established culturally. Chrisman (1989) refers to these as 'cultural templates', which supply individuals with an understanding of what they are experiencing. Chrisman suggested that people look within their 'repertoire' of health beliefs and find culturally recognised descriptions of their illness experience. The information that makes up the repertoire is derived from a variety of sources,

both personal and cultural (although arguably the two cannot be separated). The result is a specific idiosyncratic belief system:

“The illness belief repertoire is partially representative of beliefs that constitute popular health culture. Any repertoire’s specific configuration is the consequence of a person’s life experiences: his or her exposure to a limited number of the widely ranging beliefs contained within popular health culture.” (Chrisman 1989:14)

Young’s (1980; 1982) conception of prototypes similarly offered an insight into how beliefs about health are formulated. Prototypes are based on personal experiences and memories that provide clues to current events and can be shared by small groups of people, like family and friends.

The ideas put forward by Kleinman, Chrisman and Young may be thought of as a starting point for Davison and colleagues work on lay epidemiology (Davison, Frankel & Davey Smith 1991)⁶. The next section of the review will focus solely on lay epidemiology, and its constituent components of candidacy, anomalies and the prevention paradox.

2.3 Lay epidemiology

The lay epidemiology model was introduced in a series of papers beginning with the influential *Lay epidemiology and the prevention paradox: the implications of coronary candidacy for health education* (Davison, Smith & Frankel 1991). In formulating the model they drew on data generated from a series of in-depth interviews with 180 adults in three geographical locations in South Wales. The interviews were part of a study that aimed to consider the impact of health promotion programmes, and in particular how ordinary people talked about heart disease and its causes. The localities had recently been the target for ‘Heartbeat Wales’, an education campaign on CHD, and while the authors supposed that the study population was likely to be typical of any adult population in the United Kingdom, they did concede that the recent attention on

⁶ The paper cited here by Davison, Frankel and Davey Smith (1991) first introduced lay epidemiology. For ease of reading this paper and work will be referred to simply as ‘Davison’ in the body of the text. The team produced a series of papers that used findings from this study. These papers will be cited in full.

CHD may have elevated the condition in the minds of the sample population. In its broadest sense, lay epidemiology:

“refers to a scheme in which individuals interpret health risks through the routine observation and discussion of cases of illness and death in personal networks and in the public arena, as well as formal and informal evidence arising from other sources, such as television and magazines” (Frankel, Davison & Davey-Smith 1991:428)

This information is combined to build an explanatory model for Coronary Heart Disease (CHD). Such an approach, it was asserted, was akin to the approach found in mainstream epidemiology. Further, they concluded that not only was this method of theory building analogous to a scientific model but the detail of the beliefs also echoed biomedicine. Lay beliefs expressed by the Welsh cohort about the causality of CHD were littered with explanations borrowed from contemporary health promotion. Davison suggested that the ‘common currency’ among the lay community and health promoters alike was that CHD was preventable through behaviour modification. What the lay epidemiology model provided was a formula that allowed the general public to estimate the risk of CHD in oneself and others. It was this estimation of risk of CHD that Davison termed ‘coronary candidacy’, the concept at the heart of lay epidemiology.

2.3.1 Coronary Candidacy

Coronary candidacy was described by Davison as a ‘cultural mechanism’ which contained a series of widely and easily recognisable concepts associated with CHD. Together, these provided an explanatory framework for the identification of those thought to be most or indeed least likely to suffer ‘heart trouble’. Candidacy demonstrated how health beliefs were operationalised:

“Through its use (candidacy), generalised information which is derived from an aggregation of many cases is returned to the realm of the individual. It is a mechanism that helps individuals to assess personal risks, obtain reassuring affirmation of predictability (thus mapping unpredictability) devise appropriate strategies of personal behaviour and go some way towards explaining events which, by their very nature, are deeply distressing. In the cultural edifice which our society has erected to make sense of coronary disease and death, candidacy is a central pillar.”(Davison, Frankel and Davey Smith 1991:6)

Candidacy, Davison found, was used in different ways. The first, most powerful, and the most easily evoked, was the retrospective explanation of illness events and deaths in others. The commonsense view of why a CHD event had happened:

“Mind you, he was always a bugger for his fry ups and his cream cakes, so he had to be well up for it, like” (Davison Frankel and Davey Smith 1991:8)

“Of course, it was in the family, so it was to be expected really” (Davison Frankel and Davey Smith 1991:8)

Candidacy was also used to predict future illness, again in others:

“looks as if they might keel over at any point” (Davison Frankel and Davey Smith 1991:9)

“I didn’t like to say anymore cos she looked like she could have a heart attack any minute” (Davison Frankel and Davey Smith 1991:9)

“He’ll have a heart attack if he isn’t careful” (Davison Frankel and Davey Smith 1991:9)

Though some respondents also discussed personal candidacy, both in relation to past and future events, Davison believed that candidacy tended to be most salient when commenting on the health of others.

These examples from Davison’s interviewees are familiar. They represent the everyday language used to discuss heart disease and they offer valid reflections on the manner of talk around CHD. They also hint at how candidates are identified. Davison claimed that individuals sought three types of information when judging candidacy: physical characteristics, social information and personal information. Yet, it was not always necessary to access all three types of information. Obesity, or physical stature, is central to causal explanations and Davison noted that the individual’s ‘build’ was invariably mentioned in any discussion of a CHD event. Sometimes, particularly in extreme cases, only physical signs were required to confirm candidacy. Body-mass was the visual representation of CHD, and allowed speedy judgements of candidacy to be made - even about strangers. In such cases just one factor was enough to define candidacy and no further information was needed. Judgements about body-mass took on a new significance in the context of retrospective candidacy. If an

individual thought to be only slightly overweight experienced a CHD event, their candidacy, by virtue of their weight, was confirmed. Equally, if an individual was not overweight, this was also central to the discussion but prompted the beginning of speculation about alternative explanations. At this point other aetiological factors deemed important for CHD were considered. Most common amongst them were a lack of physical fitness, family history, occupation, and sometimes, for this particular population, geography. When information about behaviours or risk factors was available, this too was inserted into the explanatory model. Davison demonstrated that a personal explanatory model was attached to each individual CHD experience. Potentially complex links were made between risks. For example, worriers or those under stress were thought to be more susceptible to CHD. In turn worriers were more likely to smoke to counteract their worry, thus augmenting their candidacy because smoking is also a behaviour associated with CHD. As Davison noted:

“This type of linkage tends to give each individual an organic wholeness and a personal character” (Davison, Frankel and Davey Smith 1991:13)

According to Davison, candidacy was ‘wide’. Candidacy comprised of such a range of behaviours and characteristics that ultimately anyone could be a candidate. They illustrated this by showing that individuals located at the extremes of a behavioural spectrum could equally be candidates. Those who engaged in no physical exercise and those who take ‘too much’ exercise, are both thought to be at risk of CHD, as are manual labourers and high-flying executives by virtue of work stress.

2.3.2 Anomalous Deaths and Unwarranted Survivors

As well as the strength of the candidacy concept in providing an explanation for CHD events, a crucial element of candidacy, according to Davison, is that the lay epidemiologist is keenly aware of its fallibility. Despite its width, many CHD events occur in those who do not fit any candidacy profile. Hence, phrases like ‘the last person you’d expect’ were used, which represented a violation of candidacy. Likewise, not all candidates develop illnesses. This led Davison to stress that candidacy is simply a reflection of risk, and consolidates the public image of heart attacks as unpredictable events:

“ even though most of our informants have professed the opinion that heart disease is to some extent preventable or postponable the idea that it could happen to anyone (at any time) is omnipresent” (Davison, Frankel and Davey Smith 1991:14)

In the absence of adequate aetiological explanations luck and/or chance are arrived at as explanations. Unpredictability is seen as nothing more than bad luck. Candidacy can only provide a simple classification for heart illness episodes. The recognised fallibility of candidacy is operationalised through the identification of what the authors referred to as ‘unwarranted survivors’ and ‘anomalous deaths’. That is those individuals who meet the risk profile yet do not experience any illness events and those who do not meet any aspect of the recognised risk profile and succumb to illness, respectively:

“The popular idea of the classic coronary candidate and the common observation that candidates and victims are not co-extensive categories, both owe their existence to this interplay between publicly communicated scientific information and the operation of Lay Epidemiology” (Davison, Frankel and Davey Smith 1992:678)

Running throughout Davison’s work is a commentary on the implications of lay epidemiology for health education. His team conjectured that the failure of individuals to follow healthy lifestyle advice, despite being aware of the risks, may be attributed to lay epidemiology rather than the widespread supposition that ignorance or even fatalism are to blame (Frankel, Davison & Smith 1991). They called for a better understanding of the context in which behaviour occurs rather than relying on the, often denigrating, responses found in much health education. They suggest that the health concerns of the lay public are more aligned with conventional epidemiology than health promotion. The importance of the familial element in CHD, for instance, is strongly recognised by lay epidemiology but rarely raised in health promotion material.

“That popular beliefs systems are closer in spirit to the questioning traditions of epidemiology than to the certainties of health education has important implications for health education.”(Frankel, Davison & Smith 1991:428)

For the lay epidemiologist, lifestyle factors, they propose, are basically inconclusive. Via simple observations individuals see that behaviour modification offers little guaranteed protection from CHD. They presented the public

response to the egg scares of 1988 as an illustrative case study (Frankel, Davison & Smith 1991). The almost immediate threat of the poisonous properties of eggs dramatically and instantaneously altered behaviour, yet the advice relating to the links between eggs and heightened cholesterol had little impact. Such behaviour patterns are rational, rather than fatalistic, as much health promotion supposes.

2.3.3 The prevention paradox

Davison's formulation of lay epidemiology went beyond the simple description of an abstract concept. As already stated Davison's team offered lay epidemiology as a possible explanation for the failure of health promotion throughout their work. They utilised Rose's 'prevention paradox' and considered some of the implications of candidacy for health education.

Rose (1985) originally outlined the problematic nature of health promotion activities that focused on the population instead of the individual. He asserted that the approaches pose different questions of causality. The first 'why does this happen?' is asked of a population. The second focuses on the individual case; 'Why did this happen to this person at this time?' Though Rose encouraged his students to ask both questions, the decision to settle on either method has significant implications for preventive health strategies. An individual focus requires the identification of those in 'high risk' groups, possibly via screening programmes. Though such a method is likely to be effective, at its core is a problem. According to Rose, the ability to '*predict future disease is usually very weak*' because at risk individuals often remain healthy and vice versa. The alternative then is to adopt a population approach and '*to lower the mean level of risk factors, to shift the whole distribution of exposure in a favourable direction*' (Rose 1985:37). Rose concluded that this most radical approach presents the challenge of the 'prevention paradox'. Population measures do just that, they impact at the level of population. Therefore many people have to opt to make behavioural change in order for one individual to benefit. Nevertheless, the strategy of health education must be to raise the awareness of risky behaviours among the general population rather than targeting those who are most at risk. If CHD is used as an example, most CHD deaths occur in the mid-range of the population so many of those who change behaviour would never

have had a heart attack in any case. Yet, informing individuals that, statistically, they would be unlikely to benefit from behavioural change, is clearly problematic and challenges the success of the approach.

Lay epidemiologists, Davison suggested, recognise the prevention paradox. Heart attacks continue to happen in those that were not at risk and those at risk will continue to avoid heart attacks. Individuals are reminded of the prevention paradox by observing anomalous deaths and unwarranted survivors. This key component of lay epidemiology, Davison suggested, has been overlooked by health promoters. He used the example of advice given about saturated fat. The general population believe that all saturated fat is bad for all people. The result is a lower risk threshold across the population and individuals who never previously saw themselves as at risk now do so. Moreover, a universal lowering of the risk threshold means that there are greater observable numbers of people surviving risky behaviour. Although the numbers of those who were not at risk are reduced, their profile becomes heightened. All of this consolidates the fallibility of candidacy, and calls into question the entire notion of 'risk' among the general population. The population approach moved Davison to accuse health educators as 'propagating half-truths' that continue to be delivered with 'zeal'. Yet, Davison conceded that highlighting the prevention paradox within health promotion material would threaten its *raison d'être*.

Hunt and Emslie (2001) in their commentary on lay epidemiology and the prevention paradox challenged Davison's original assertions. While they broadly agreed with Davison's model and in particular supported the strength of the candidacy concept, they were keen to emphasise the differences between the two strands of epidemiology. First, they proposed that it is the individual, and not the collective, that ultimately concerns the lay epidemiologist. They based this on the premise that although illnesses and deaths at a population level can be observed, the level of detail available is insufficient for the events to be truly meaningful:

"However, we could contend that events within the family are particularly salient in deconstructing candidacy. Thus, if a family member is an unwarranted survivor or more particularly an 'anomalous death' this has particular power in undermining the

acceptance of well-established epidemiological facts about risk factors for major disease.” (Hunt & Emslie 2001:445)

So it is the close experience, according to Hunt and Emslie that shapes understanding of health and risk. They go further and, using a research analogy suggested that the lay epidemiologist, in monitoring family events, is more akin to a qualitative researcher:

“The emphasis is not on isolating risk factors, but on contextualising, qualifying or even rejecting previously accepted risk factors or aetiological theories in the face of contrary personal experience.” (Hunt & Emslie 2001 pg. 445)

Additionally, they highlighted a difference in the way in which inexplicable events are dealt with. Within formal epidemiology hypotheses change slowly across decades to accommodate previously unfathomable occurrences. Such a process is unlikely to satisfy the lay epidemiologist, whose need to make sense of an incongruous family event is ‘more immediate and compelling’. Hunt and Emslie concluded by supporting moves towards acknowledging the inherent value in lay knowledge and its potential for augmenting understanding of risk estimation.

2.3.4 Lay Epidemiology and fatalism

In a further paper that also utilised data from the South Wales study Davison and colleagues turned their attention to an analysis of fatalism and lay epidemiology. Davison previously asserted that the ‘common currency’ among the lay public and health educators was that CHD was largely avoidable through behavioural change. Fatalism has often been proposed as a reason for failure to adopt healthy behaviours and affect such change (Pill & Stott 1987). Though fatalism has been used as a wholly pejorative label signifying ignorance and irrationality, it has also more loosely represented the perception that health lies out with the control of the individual. It is the latter interpretation, where health can be neither controlled nor predicted, that Davison and colleagues supposed challenged health education.

The logical corollary to candidacy’s failure to correctly predict all CHD events is significant for fatalism. Davison’s informants in the South Wales study identified

three factors that they could not influence, that nevertheless impacted on their health. These were inherited personal characteristics, the social environment, and the physical environment. The social environment included occupational hazards and socio-economic status. Davison suggested a further fourth field, luck or chance, which is not a discreet entity but rather is *‘a process or mechanism governing the first three’* (Davison, Frankel and Davey Smith 1992). Davison proposed that lifestyle ‘choices’ cannot be separated from any of the three uncontrollable fields. Individuals are unable to compartmentalise discreet categories because choices are rarely made in isolation. Instead choices are made in the context of broader social, cultural and economic factors. Integral to all of these explanations of health and choice were luck and fate. Often these probabilistic notions were intertwined with religious ideas and metaphors that evoked time, for example, when ‘it’s your time’, or what Davison called ‘missile’ analogies and gambling and gaming metaphors, like ‘luck of the draw’.

Davison concluded with a plea to for health education to be cognisant of the general public’s acknowledgement that prediction is weak because of the perceived powerful influence of ‘fate’:

“The fact remains, however that within the general statistical tendencies that can be observed within populations, there lies a more chaotic distribution of illness and death. Some fat smokers really do live till advanced old age, and some svelt joggers really do ‘fall down dead’”. (Davison, Frankel & Davey-Smith 1992:683)

Similarly, Frankel, Davison and Davey Smith (1991) used the example of heredity and risk associated with CHD to illustrate the problematic nature of modern health promotion. Both epidemiology and lay epidemiological perspectives place emphasis on the importance of family history as a risk factor, yet this is not found in educational material. Neither is the widely acknowledged social patterning of health experience:

“That popular belief systems are closer in spirit to the questioning traditions of epidemiology than to the certainties of health education has important implications for health education” (Frankel, Davison & Smith 1991:428)

2.4 The scope of lay epidemiology

Davison's original article has been cited frequently. Armstrong's (2003) audit of papers published in the first 25 years of the *Sociology of Health and Illness* found it to be the second most cited paper in the history of the journal, having been cited 99 times. It continues to be widely cited having been referenced 300 times⁷. Though lay epidemiology has clearly been influential, the concept has rarely been built on or developed. Only a handful of studies, which will now be reviewed, have taken lay epidemiology as their starting point.

Data generated from interviews in the West of Scotland Twenty-07 study provided the opportunity for some of Davison's original findings to be tested (Hunt, et al 2000). The study sought to examine relationships between family history, smoking status, other health promoting behaviours and candidacy. They found that around 40% of respondents believed that they had a family history of illness and within that heart disease was the most commonly cited. The number of relatives who had had heart disease was a significant predictor of perceived family history. Candidacy for heart disease was also strongly linked to perceived family history. Lifestyle and stress were thought to be an important cause of heart disease by those with and without a perceived family history. Though those with a perceived family history of heart disease, however, were more likely to think lifestyle factors 'very important' in explaining heart disease. Similarly both groups thought that following a healthy lifestyle was 'particularly' important for those with a family history of heart disease. Few, in either group, endorsed the 'fatalistic' elements included in the surveys. They found that those that perceived themselves to be at high risk of heart disease were less likely to smoke.

Clarke, Clotty and Pearson (1997) considered lay epidemiology in the context of cholesterol testing. Individuals who had been informed that they had raised serum cholesterol levels were interviewed twice - after the initial test, and again three months later after a second cholesterol test. In the intervening period cholesterol levels had dropped significantly. Interview data suggested that though participants did have ideas about candidacy, these were personal

⁷ Retrieved October 1st 2010 www3.interscience.wiley.com/journal/119351868/abstract

and not uniform throughout the group. The only common predictor of candidacy was being overweight. Anomalous candidates who did not fit the picture, particularly by being skinny, were thought to be unfairly afflicted with high cholesterol. Interestingly, Clarke and colleagues asked participants to comment on their personal behaviours. Most of those interviewed believed that the result of their second test was not an accurate reflection of their behaviour between tests. Not only were some disappointed that their behavioural changes had not made a greater impact on their cholesterol levels but others acknowledged that they had made few changes yet had good results. They concluded that far from being irrational or fatalistic in their beliefs about behavioural change, participants produced rational reasons for their choices:

“.... what I haven’t had proved to me - is that sacrifice in 20 years time going to prevent me from having a heart attack? If I knew it was, then alright, then I could make the sacrifice, but when it is so unsure as to whether it is going to do it, why should I make the sacrifice” (Clarke, Crotty and Pearson 1997:219)

Lawlor et al (2003) suggested that lay epidemiology may account for the failure of smoking cessation programmes in deprived communities. The authors noted that although there has been a marked reduction in the overall smoking rate in the UK and the USA, this has not been consistent across all social classes. By 1999 only 13% of men in social class I smoked, compared with 44% in social class V. Further, they demonstrated that while the health benefits have been obvious for those in Social Class I, they are less so for social class V; not until 1991 did the all cause mortality of men in social class V fall to the level that men in social class I enjoyed in 1931. They suggested that improvements in overall health are required as catalysts for the adoption of health promoting behaviours, like smoking cessation. Indeed they proposed that if the daily lives of men in social class V are more hazardous (as can be seen by the high level of mortality from accidents), then smoking poses no immediate threat:

“The hazardous environments faced by individuals from lower social classes affect their likelihood of quitting smoking not only because dealing with such circumstances takes precedence over smoking cessation but because within these environments smoking is often an important pleasure and coping mechanism.”(Lawlor 2003 269)

The authors concluded that smoking cessation must have easily observable benefits, and via the mechanisms provided in lay epidemiology, this has not occurred for those in social class V. The operation of lay epidemiology therefore accounts for the relative failure of smoking cessation programmes amongst the most deprived. Similarly, in their commentary on sun exposure and health risks Ness et al (1999) proposed that from a lay epidemiological perspective sun exposure offers more benefits than harm. The numbers of people dying from skin cancer are relatively low and they claimed that there are some diseases, like cardiovascular disease, mental health and dermatological conditions that benefit directly from sun exposure. They cautioned against the reduction of vitamin D exposure which potentially has adverse effects. They concluded that lay epidemiology is 'ahead of medical thinking' and ask that more definitive data on the risks associated with sun exposure is presented. This position is questioned by evidence from Australia. Australia has the highest level of skin cancer incidence in the world and Sinclair & Foley (2009) suggested that campaigns around safe sun messages have been successful in reducing the overall melanoma incidence. Arguably what has been achieved in Australia is a cultural shift in attitude towards sun exposure. Such a change, Rose believed, would reduce the effect of the prevention paradox. Miller (2005) used the lay epidemiology model to explain the behaviour of injecting drug users (IDUs) in Australia. He found that his respondents' risky behaviour was justified by the landscape of drug use and illness in one particular community, rather than mainstream health education. This chimes in, not only with Davison's finding about the influence of community observations but also, given the size of Miller's population, Hunt and Emslie's (2001) commentary that emphasised the importance of 'family' experience in defining beliefs.

Such studies prompted Allmark and Tod's (2006) to question '*How should public health professionals engage with lay epidemiology?*' Here they set out the ethical arguments around public health's engagement with lay epidemiology. While they acknowledged the power of the prevention paradox, they supported the need for public health messages that are 'meaningful'. They questioned the ethics of public health challenging what may be seen as core cultural values in communities, but accept that in state-funded health services such challenges are more acceptable. They concluded that by being mindful of the mechanisms

in lay epidemiology, public health may have more success. Similarly Watterson (1994) and Bury (1994) in earlier papers called for health educators to take more notice of lay epidemiology. Bury (1994) referred to public responses to health promotion as largely a 'black box'. He looked to health beliefs literature generally and lay epidemiology more specifically to demystify these notoriously complex relationships. Both authors suggested that if the unpredictable nature of health and illness is at least acknowledged by health promotion this may engender greater public confidence in preventive strategies.

Many of the papers that have cited Davison's original work focus broadly on lay understandings of CHD. For example, Smith et al (1999) conducted a large quantitative survey of Australian residents that was designed to ascertain the estimated preventability of a number of common conditions including skin and lung cancer, CHD, and diabetes. While Davison claimed that people commonly believed that CHD was preventable, only a small number of respondents in Smith's survey concurred. Instead most (44%) thought that CHD was sometimes preventable. Of all the diseases surveyed diabetes was thought least preventable. They concluded that individuals generally under-rated the preventability of conditions. Preston (1997) in an ethnographic study of CHD-risk families echoed Davison's work. According to Preston, the families had a clear view of what a coronary candidate 'looked like' and when people who had suffered CHD did not fit the ideal type it caused 'conflict' in their belief systems. Preston demonstrated that families opted into only those health-giving behaviours that fitted into already established lifestyles, rather than adopting an entire regime change. Again the importance of luck and fate in risk models emerged from Preston's data. Wiles (1998) was primarily concerned with rehabilitation following a heart attack and found that participants had fixed notions of coronary candidates and described many anomalous CHD deaths. This led participants to conclude that their recovery would be governed by fate and luck rather than lifestyle modification. In a west of Scotland study that considered perceptions of family history and CHD, Emslie and colleagues found, as is consistent with the other studies, that respondents described an explanatory model of CHD that included a range of behavioural, lifestyle and hereditary factors (Emslie, Hunt & Watt 2001a). Unlike other studies, respondents in this study introduced structural factors which may be explained

by the prevalence of socio-economic disadvantage in the west of Scotland. Both the unpredictability and speed of heart disease was noted. Heart attacks were therefore regarded as a quick, and relatively painless, death. These views were often discussed in the context of other family illness experiences that were slow and painful, like lung cancer. Heart disease and heart attacks in old age were viewed positively. Drawing on data from the same study, Emslie, Hunt and Watt (2001b) questioned the omission of gender in Davison's original analysis. They argued that masculinity is central to coronary candidacy and that anomalous deaths and unwarranted survivors too, are a wholly masculine concept. This led them to conclude that the language used is misrepresentative. When Davison used the term CHD, this actually referred to 'heart attacks', rather than the chronic morbidity which is more commonly associated with women. They also questioned the connection between candidacy and age. In the original model of candidacy, Davison paid little attention to age, and claimed that 'after the age of about 40, candidacy seems to increase with age'. Emslie and colleagues argued more attention be given to the importance of age in the candidacy model. Older people dying of CHD were thought to have died of old age more than CHD, thus negating the need to consider candidacy. A further paper from the same team (McConnachie et al 2001) considered the presence of 'anomalous deaths' and 'unwarranted survivors' in a west of Scotland cohort. They examined visible risk factors - smoking and BMI, together with less visible risk factors like blood pressure, cholesterol, social class and deprivation. They found that visible risk factors were useful predictors of death from CHD. Those who may be regarded as unwarranted survivors had fewer non-visible risk factors than their counterparts. Similarly those judged to have an anomalous death had a higher non-visible risk profile than others in the low risk group. This echoed Marteau et al's finding that the lay epidemiologist is more likely to rely on visible risk factors than non-visible factors like cholesterol, primarily of course, because they can only access visible risk factors (Marteau et al 1995). Another study that aimed to redress the gender imbalance in the study of CHD was carried out by Ruston and Clayton (2002). They interviewed women at high risk of CHD who they found arrived at ways of working a lower personal risk into their estimation. This was done by simply assuming that men were at greater risk, especially by virtue of their employment. They point out that not only do

women rarely feature in qualitative studies of CHD but they were routinely excluded from large quantitative explanations.

In a study concerned with the development of an intervention aimed at changing health behaviours, Angus et al (2005) questioned high risk individuals about their risk of CHD. They found that mechanisms similar to the lay epidemiological model were employed by focus group respondents to estimate risk. Interestingly Angus cited many studies including Davison's work and that of Emslie, Hunt & Watt (2001b) that illustrated a wide variety of terms to describe CHD, including a 'dicky-ticker'. Davison reported that often CHD and the attendant high risk behaviour was often discussed in humorous tones. Yet, Angus portrayed a different picture of talk about CHD, referring to it as a 'sneaky' disease, with participants emphasising the unpredictable nature of CHD. This type of language is more usually associated with talk about cancer (Lupton 1994), which will be discussed in more detail in Chapter 3.

Frich et al's (2007) study focused on portrayals of candidacy amongst a high risk cohort suffering from familial hypercholesterolemia in Oslo. They found that even amongst this high risk group, traditional images of candidacy were strong and settled on older men who engage in high risk behaviours. They shared Emslie's assertion that candidacy is an exclusively masculine concept and for that reason many female participants frequently found the reality of their own risk difficult to accept. Younger participants who had few cardiac events in their family situation were most likely to reject candidacy and think instead that CHD could happen to anyone. Many were keen to make distinctions between those who could and could not be held responsible for their own risk status, and often sought to distance themselves from traditional candidates. Commenting on the morality of typical candidates' behaviour provided this distance. As with most of the studies already reviewed the uncontrollable factors - fate and luck - were emphasised, which extended to those thought lucky enough to have strong constitutions. While this study obviously focused on a high risk group, their familial link was only one among many factors considered when arriving at their personal risk assessment. In an almost identical study in the UK, Weiner (2009) also found that participants offered biomedical as well as genetic explanations of familial-hypercholesterolaemia. As with the Norwegian cohort, Weiner's participants made clear distinctions between 'inherited cholesterol' and

‘ordinary cholesterol’. Weiner noted though that participants offered examples of modifying their behaviour in an attempt to reduce their overall risk. This, Weiner argued allowed them to remain morally intact: they were taking responsibility for their own health. Weiner found that the idea of Davison’s ‘coronary candidate’ was tenacious amongst this high risk group and like Frich’s found that heredity was only one element in the candidacy profile. Weiner proposed that despite Emslie, Hunt and Watt’s (2001b) contention that gender was largely missing in lay accounts of CHD, women involved in her study allied themselves to the typical male candidate type.

2.5 Lay epidemiology & Cancer

Few studies consider cancer and lay epidemiology. Salant and Gehlert’s (2008) study looked specifically at breast cancer and took lay epidemiology as its starting point. The focus group study with African-American communities in Chicago set out to explore respondents’ meaning and understanding of breast cancer. Respondents yearned for more simplicity, for pesticide-free food, pollution-free environments and settled on the idea that old-fashioned living was largely risk free. Aetiological explanations, therefore, focused on ‘modern’ living. They found that stigma and fear continued to be associated with breast cancer, and especially the ‘risk of knowing’, which might explain women’s reluctance to engage in screening programmes. Ignorance provided protection. Related to this was the belief that stress could cause cancer and the worry connected with ‘dwelling’ on cancer was itself a risk factor. Breast cancer candidacy was based on a number of behaviours like smoking and drug and alcohol use, as well as hereditary factors and age. Like Clarke, Crotty and Pearson (1997) Salant and Gehler found a personal, rather than collective, model of breast cancer candidacy. Personal risk estimations rarely featured in everyday thoughts and it was not ‘unless it hits home’ that it enters reality. The study concluded that ‘community’ beliefs dominated explanations of causality:

“Through shared experiences of disadvantage and perceptions of competing disease risks, community-level understandings of breast cancer risk helped to explain the absence or invisibility of the breast cancer ‘candidate’ from everyday risk perceptions.” (Salant & Gehlert 2008:613)

2.6 Conclusion

This chapter has dealt with beliefs about health. Details of a series of studies were outlined and collectively they demonstrate the sophistication of lay views of health. The studies have important commonalities. There are significant moral undertones present in many of the views expressed and often this manifests itself in a reluctance to 'blame' individuals for their illness. Related to this is scepticism around the preventability of diseases. Such studies though must be located in their historical context and it could be argued that they emerged at a time when the concentration on risk and preventability in health promotion was not well established. Lay epidemiology however emerged from a somewhat different cultural and political climate where the emphasis was firmly placed on individual responsibility for health. Davison's model described the framework used by ordinary individuals when arriving at beliefs about health generally, and perceptions of risk for coronary heart disease, more specifically. Davison and colleagues' work in South Wales uncovered an easily recognisable coronary candidate. Mainstream risk factors were integral to coronary candidacy but crucially the model had well recognised short-comings. The consequence of this, Davison proposed, was scepticism around the avoidance or preventability of CHD. Although lay epidemiology has been influential it is arguably under-developed. Those few studies that have drawn directly on Davison's work have found an enduring image of coronary candidacy. These studies also highlight the moral discourse entrenched within views about health. Some of those that focused on high-risk populations because of genetic predispositions, concluded that participants wanted to distance themselves from personal responsibility and were keen to stress the culpability of others. This represents a shift from the earlier health beliefs studies where participants generally shied away from apportioning blame. A small number of studies have explored lay epidemiology's relevance in other disease categories. Only one study considered lay epidemiology in the context of cancer (Salant & Gehlert 2008). Candidacy for breast cancer was not as salient as coronary candidacy. The next chapter will explore lay understandings of cancer more closely.

3. Understanding Cancer

3.1 Introduction

Psychosocial oncology is represented by a large, inter-related and, often unwieldy, literature. Each stage of what is commonly termed, the cancer journey, has been explored and the experience of patients and their carers well documented. Cancer-related interventions too, like screening programmes and palliative care, have been given frequent attention. Studies that attempt to ascertain knowledge of, and awareness about, cancer are also included in this broad genre. These commonly concentrate on understanding of risk factors and recognition of symptoms. In addition, many studies can be found that present the nuances of experience and beliefs about cancer amongst various social and demographic groups.

Given the abundance of material, the challenge for this thesis was pinpointing those areas of literature that were of most relevance. Essentially this section of the review must establish two things. First, what do lay people know and think about cancer? Second, what is the cultural position of cancer in modern 21st century society? As the previous chapter outlined, lay epidemiology is fundamentally about the recognition of risk both in oneself and others. With this in mind the literature under review here will focus on awareness and knowledge of 'risk' in relation to cancer. It must be noted that there will be some degree of overlap with awareness of risks and symptoms and such studies will not be excluded. Those that focus solely on awareness and knowledge of cancer symptoms, without dealing with risk or causation, will not be reviewed, for a recent example see Robb et al (2009). Other literatures that were judged irrelevant were those that had screening, and similar preventive behaviours, as their main focus. Further, as has been previously specified, this study has looked at cancer as a generic disease rather than the more usual site-specific approach but studies that were concerned with particular cancer sites are included.

This chapter will therefore be divided in two. The first sections from 3.2-3.6 will look at what people know about cancer, and include cancer awareness, cancer risk and cancer ethnographies. The focus will be on the biomedical

understanding of cancer. The second section 3.7-3.10 will look at the cultural position inhabited by cancer, providing an insight into the social understanding of cancer and the media representation of cancer. Together the sections will give a picture of what cancer means.

3.2 Cancer Risk Factors

Cancer is a complex disease and the multisite nature of the disease means that there are a number of known risk factors. There are also a series of reported risk factors, for instance, mobile phone use, that are questioned. It is beyond the scope of this thesis to provide a detailed breakdown of risks per cancer site and a review of the evidence regarding individual risk factors. However, it is helpful to be aware of the information available to the lay public about cancer risk factors. To this end, the information available from Cancer Research UK, is presented. Cancer Research UK is the country's largest and most widely known cancer charity. The charity has a website that provides a great deal of information about cancer to the public, patients and professionals alike. Table 1 gives detail of the risk factors, according to Cancer Research UK, that have been linked with cancer. Some are well-established, others are, more controversial

Table 1 Cancer Risk Factors *

Established	Behavioural	Biological	Environmental	Psychological
	Smoking Sun-exposure Obesity & Dietary Factors Low levels of physical activity Alcohol Sexual Activity	Virus Age Hormones	Asbestos Radon Shift work HRT X-rays	
Reported			Cosmetics & hair dyes	Stress
			Cancer clusters Pollution Plastic bottles Powerlines Mobile phones Air travel Pesticides	Trauma

* The information in this table can be found on Cancer Research UK's website. www.cancerresearchuk.org

3.3 What do the public know about cancer?

3.3.1 Historical Perspectives

The American Cancer Society carried out its first survey of cancer awareness among the public in 1948. Since then, in the numerous studies that have followed, the main focus has tended to be the public's knowledge and awareness of warning signs or symptoms of cancer, though some do include more general questions about cancer incidence and risk factors. For instance, Horn and Waingrow (1964) provided an overview of the American Cancer Society's cancer awareness survey and chart changes in responses to surveys over three time periods 1948, 1955 and 1962. They showed that over the 14 year period fewer people believed that cancer was contagious, more people would be willing to work next to someone who had cancer, and more thought that someone could have cancer but not know it. Interestingly, one of the aims of the public education campaigns was to discourage the association between cancer and old age (now an accepted association) and the authors concluded that awareness in this area too was improving. Cartwright and Martin (1958), in a study intended to assess awareness of tuberculosis, offered an interesting insight into popular views of cancer aetiology. In series of interviews with adults in Edinburgh they found that the most frequently reported cause of cancer was trauma via a knock or a bruise, followed by smoking, environmental factors like pollution, heredity and finally stress. They found that younger interviewees were more likely to opt for smoking and environmental causes, while those in older age groups were more likely to mention physical trauma. In a more recent, but admittedly dated study, Luther, Price and Rose (1982) presented data from the first 'random digit dialling' questionnaire in the United States that attempted to gauge levels of cancer awareness amongst the US public. They found that almost three quarters of respondents believed that smoking was the most likely cause, followed by food and drink, pollution, chemicals and sun exposure.

3.3.2 Awareness in the information age

In the context of psychosocial oncology as a whole, relatively little research examines or explores the general public's view of cancer. A number of large population based cross-sectional questionnaire studies have been carried out

that provide details of what the general public believe to be risk factors for cancer. Breslow and colleagues (1997) accessed views of 12,000 members of the general public in the United States and they concluded that knowledge of cancer risk factors was poor. Respondents were unable to make connections between cancer and increasing age, between bowel cancer and dietary factors, and between sexual activity and cervical cancer. In a similar, smaller study of UK adults, Wardle et al (2001) asked respondents to identify risk factors for cancer from a prescribed list. The list included established causes, like smoking, dietary factors, viruses and infections and those labelled 'mythic' or 'distracter' items like stress, pollution and living near power lines. The strongest association was made between smoking and lung cancer, and smoking was identified as a risk factor for all cancers. Most were aware of the links between number of sexual partners and cervical cancer risk. Neither family history nor age were considered important risk factors. Amongst the mythic causes, stress was the most frequently selected risk factor, particularly for breast cancer. Food additives and pollution were thought to be significant in bowel and lung cancer respectively. They also found that awareness was socially patterned and both women and those with higher levels of education were more likely to correctly identify risk factors. The authors concluded that although few respondents had selected mythic causes, adults in the UK had a poor awareness of cancer risk factors.

A similar methodology was employed to provide baseline information for Cancer Research UK's education programme in 2004 (Redeker et al 2009). As with Wardle et al's study, questionnaire respondents were offered both established and mythic risk factors. The findings were similar. The link between smoking and cancer was almost universally accepted. Three-quarters of respondents in this study were aware of the association between sun exposure and skin cancer. Both alcohol consumption and obesity were selected as risk factors by a third of respondents. Stress was again the most common mythic risk factor and 'living near power lines' too was endorsed. Common misconceptions also featured in Stein et al's telephone survey (Stein et al 2007) which calculated a health literacy score for respondents. Literacy, and therefore awareness, was patterned according to socio-demographic variables. Lower awareness was found among men, older adults, non-whites and those on low incomes. Adlard and

Hume's (2003) study in UK general practice however found that questionnaire respondents were likely to opt for known risk factors like smoking, diet and alcohol, rather than misconceptions like vitamin tablets and power cables. As well as smoking and infections, stress was also widely identified as a risk factor in a Japanese population study (Inoue et al 2006) where family history and genetics were also thought to be important. The significance of family history as a risk factor for breast cancer was also identified in an Australian study that looked at a series of common cancers (Reeder & Trevena 2003). More than half the respondents failed to name any risk factors for breast cancer and the vast majority were not aware of any of the risks associated with prostate cancer. Respondents were clear though about the risks attached to both smoking and sun exposure. Makris et al (1994) in a large quantitative study of University students in Greece found that awareness of risk factors and causality was poor across cancers. One study (Murray & McMillan 1993) that aimed to look specifically at gender differences in beliefs about cancer found that cancer was the most feared disease generally, though women were more fearful than men. A factor analysis found that most saw stress, health behaviour and environment as important causal factors, though gender differences in perceived causality emerged - men were more likely to believe that cancer was caused by behaviour and women by heredity. Conversely, Thomas & Fick (1993) found that men were more pessimistic about cancer detection and outcomes than women. Fatalistic attitudes were found to be widespread across the American population by Niederdeppe & Levy (2007), with around half their respondents believing that *"it seems like almost everything causes cancer"*. They found that such beliefs were concentrated among those less educated and that whites were more likely to be fatalistic than those from other minority-ethnic groups. Those who engaged in positive health behaviours were less likely to be fatalistic.

The above studies show that awareness of cancer risks is at the same time erratic and relatively predictable. It comes as little surprise that, without exception, smoking was selected as a significant risk factor by almost all respondents across most studies. The identification of other risks is readily explained by local idiosyncrasies. Infection in Japan or sun exposure in Australia reflects the higher incidence of gastric cancers and melanoma and in each of these countries. What these risk factors have in common is media attention on

the cancer-site, risks and prevention. Given the lack of publicity prostate cancer receives, it is unsurprising that 80% of respondents failed to name any risk factors (Reeder & Trevena 2003). Knowledge reflects readily available information. Concentration on environmental or genetic risk factors in individuals' models indicate mass media fixation with these areas. One paper (Stein et al 2007) was critical of the media's unnecessary concentration on the importance of pollution and recommends investment in smoking cessation programmes.

The studies hint at a tendency for respondents to accept false causal relationships between 'mythic' factors and cancer (Breslow et al 1997, Wardle et al 2001, Redeker et al 2009). Such conclusions lead to calls for improved information but perhaps the value of including such falsehoods requires consideration. Methodologically, questionnaires fail to capture reasoning and a greater understanding is needed of why stress is so widely regarded as a risk factor for cancer. Moreover, one might argue that the very inclusion of misconceptions in questionnaires exacerbates misunderstandings. Providing prescribed lists of risks may simply prompt endorsement and Waller and colleagues (Waller, McCaffrey and Wardle 2004) found extremely poor unprompted recall of warning signs and risks for breast and bowel cancer and when prompts were offered levels of awareness improved greatly. Their study leads them to conclude that studies of awareness that provide a tick-box format may be overestimating knowledge and awareness.

3.3.3 Site-specific knowledge

More common than studies that aim to gauge general awareness about cancer are those that have adopted a site-specific approach to cancer awareness. Both breast and colorectal cancer are frequently considered. Oral, skin, gynaecological, and urological have been surveyed less frequently. Few studies have looked specifically at lung cancer despite its impact on mortality.

Studies that reported awareness of breast cancer show that perceptions of risk are poorly understood (Ibrahim 1991; Paul et al 1999; Grunfeld et al 2002; McMenamin et al 2005; Linsell et al 2008). Assessments of lifetime risk were wildly underestimated: almost a third of respondents thought that their risk was

one in a thousand (Grunfeld et al 2002) and another study found that half of all respondents judged their lifetime risk as one in a hundred (Linsell et al 2008). Other studies reported the over-estimation of risk (Paul et al 1999; Wilcox & Stefanick 1999; McMenamin et al 2005). Knowledge about risk factors is equally poor. In particular the association between older age and breast cancer is recognised rarely. Most women believe that breast cancer is a disease that affects younger women. There is some evidence that the over-estimation of risk has increased since the 1980s (Paul et al 1999). Understanding of life-style factors in relation to breast cancer is both limited and erratic across countries (Peacey et al 2006). Stress is commonly thought to be a risk factor (Payne 1991).

Risks for colorectal cancers include age, family history and lifestyle factors. Awareness of these links is variable. In a European comparison, Keighley and colleagues (2004) found that neither age nor family histories were recognised risk factors. Although diet was reasonably well recognised, few made connections between physical inactivity and colorectal cancer. An earlier British study (McCaffrey, Wardle and Waller 2003) reported that the majority of participants could name no risk factors for colorectal cancer and awareness of the importance of age, family history or diet was extremely poor.

Studies that have considered public awareness of oral cancer have found that only a little over half of the sample were aware of the very existence of oral cancer (Warnakulasuriya et al 1999; Horowitz, Canto & Child 2002). More recently overall awareness has improved and there is widespread recognition of the connection between smoking and oral cancer, though the evidence about the impact of information on high risk groups is mixed (Lowry & Craven 1999; Humphris, Freeman and Clarke 2004). Understanding of the links between alcohol and oral cancer is less well appreciated (Lawoyin et al 2003; West et al 2006; Elango et al 2009). Smoking is a well-established risk factor for both lung and oral cancer but recognition of its role in other cancers is weak. Neider et al (2006) in a study of bladder and renal cancer found that just under a third of respondents correctly identified the association between smoking and urological cancers compared with 98% who made the links between smoking and lung cancer. More recent data suggested that awareness of such links has improved slightly (Anastasiou et al 2010). Fitzpatrick et al's study of prostate cancer (Fitzpatrick et al 2009), found that awareness of risks, like age and family

history were good but respondents were less sure about the role of behavioural factors. Again they reported startling misconceptions, for example 10% of the non-patient sample believed that prostate cancer affected men and women equally. The international study also found variation by country, for example, 28% of German men believed that they could reduce prostate cancer risk by not carrying their mobile phone in their pocket. The authors concluded that awareness had improved since their previous study (Schulman, Kirby & Fitzpatrick 2003) but that overall personal risk perception was poor.

Gynaecological cancers fare little better. A series of studies have shown that the initial failure to make links between sexual activity, HPV and cervical cancer has improved (Buga 1998; Pitts and Clarke 2002; Waller, McCaffrey & Wardle 2004; Marlow, Waller & Wardle 2007). The recent introduction of the HPV vaccine provided an opportunity for the discussion of the sexual transmission of the virus and successfully raised awareness of the risks associated with HPV and cervical cancer (Gerend & Magliore 2008). Ovarian cancer is less researched and consequentially less understood, though knowledge is improved with experience via a friend or relative (Lockwood-Rayermann et al 2009). Although the risks of sun exposure are well established in some countries (Reeder & Trevena 2003) they remain poorly understood in the USA (ADA 1995) and the UK (Hiom 2006). Sun exposure in the UK is believed to be harmless and the appetite for sun-bed use remains buoyant and the risks under-appreciated (Amir et al 2000).

The startling omissions amongst these site-specific studies are studies that consider lung cancer. Though it may be argued that the almost universal recognition of the links between lung cancer and smoking negate the need for such studies.

Overall, investigating the knowledge and awareness of risk factors for cancer amongst the lay public is a neglected activity. Any review of the available data demonstrates that if information is provided awareness increases. It might be assumed that levels of awareness had improved dramatically since the original American Cancer Society surveys but when considered more closely, the picture is more complex. Improving awareness has not been a steady and equitable process. Some cancers have fared better (or worse, depending on your view point) than others. Moreover certain aspects of information seem to have been

embraced more readily than others. For example, Barrat et al (1997) found that awareness of mammography as a detection tool for breast cancer had more than doubled in the eight years between 1988 and 1996 but that respondents possessed a scant understanding of risk. The responsibility for levels of awareness and variation in knowledge can be at least partly attributed to media coverage. Much has been written about the predominance of breast cancer in the mass media (Gottlieb 2001). Yet, those areas where less is known or certain about risks within the scientific community are unlikely to be fully grasped by the lay public. The emergence of the importance of genetics for certain cancers has impacted on understanding and awareness. This is something that will be returned to in the coming sections on risk, the cultural position of cancer and the overall treatment of cancer in the media. For instance, around half the women surveyed endorsed a link between family history and ovarian cancer but genetics explain only 10-15% of cancers (Lockwood-Rayermann et al 2009).

The studies reviewed thus far illustrate changes in awareness over time. Clearly publicity has an impact. The early studies from the American Cancer Society were keen to encourage a move away from the supposition that cancer was a disease that simply affected older people. The challenge facing health educators today, particularly with breast cancer is to re-establish age as a significant risk factor.

3.3.4 Variations in cancer awareness

Many of the studies reviewed have reported different levels of awareness based on socio-demographic variables like education, socio-economic status and gender. Those with higher levels of education were judged to be more knowledgeable about cancer in a number of studies (Weinrich et al 1992; Breslow et al 1997; Ratnasinghe, Weed & Shankar 1999; Wardle et al 2001; McCaffrey, Wardle & Waller 2003). Weinrich et al (1992) also found that those with higher levels of income possessed greater cancer knowledge. Typically, women are reported to be more knowledgeable than men (Wardle et al 2001; McCaffrey, Wardle & Waller 2003).

In their review of health beliefs, cancer and ethnicity, Pfeffer and Moynihan (1996) documented the lack of relevant British research. They outlined the common problems associated with gathering meaningful health beliefs data and

make a plea that this is approached with more sensitivity. They also found that most studies of ethnicity and health focus on a single 'ethnic' group, rather than compare the ethnic minority with the white majority. More recently Scanlon & Wood (2005) found that there were significant differences in breast cancer awareness both between different minority ethnic groups and between those groups and the general population. The same is not true of the United States where ethnicity is always considered and reported. Dein (2004) provided an overview of research on attitudes towards cancer across the world and demonstrated that there are a plethora of studies that highlight the cultural nuances apparent in explanatory models of cancer (Perez-Stable et al 1992; Mishra, Aoulua & Hubbell 2000; Estape et al 2003).

3.4 Understanding Cancer Risk

Estimating risk through the mechanism of candidacy is central to lay epidemiology. Candidacy relates to evaluations of risk not just in others but also in oneself, although admittedly it was more effective judging others' risks. In the previous section awareness of cancer risk factors was reviewed. Knowledge and awareness of risk factors are crucial for the development candidacy models. This section will look at the perception of risk in relation to cancer.

3.4.1 Cancer and the 'risk society'

Risk has become an issue in late modernity. Both Beck (1992) and Giddens (1991) have developed discourses around 'risk society', which at its most basic refers to a society preoccupied with the future. A detailed examination of the concept of the risk society is beyond the scope of this thesis but the idea is relevant to perceptions of cancer risk in a number of important ways. First, where once the major threats were natural disasters that were volatile and attributed to acts of God, risks are now thought to be man-made and posed by society itself. Risk has become central to the way we think about cancer. First, we are aware of the importance of behavioural risk factors in the development of cancer. Moreover there are links, albeit contested, between environmental factors and cancer. Related to this is the shift towards individual responsibility for health. While risks were once experienced at a societal level, risks in the 21st century are faced by individuals. This is extremely important in how we think about health in

general and cancer more specifically. Epidemiologists construct risk estimates which are then used by health promoters and educators. The way in which messages about risks were communicated was key for Davison and colleagues in explaining the resistance to behavioural change. Resistance or non-adherence to health promotion messages that ask people to change their behaviour introduces a moral dimension to the risk discourse. The responsibility to engage in good behaviours and thus avoid disease lies with the individual (Giddens 1999). If people are able to avoid risk, are they able to avoid cancer? If so, according to Lupton, risk adopts a 'moral' tag (Lupton 1993; 1995):

“ when risk is believed to be internally imposed because of lack of willpower, moral weakness or laziness on the part of the individual, the reciprocal relationship of sin and risk is reversed. Those who are deemed to be at risk become sinners, not the sinned against, because of their apparent voluntary courting of risk.” (Lupton 1995:90)

Moral judgements are common in cancer narratives and this will be returned to in greater depth in the later section on cultural understandings of cancer.

3.4.2 Cancer and perceptions of risk

Theories of behavioural change, like the health belief model (Rosenstock, Strecher & Becker 1988) and the theory of planned behaviour (Ajzen 1991), have at their core a requirement to recognise and appreciate risk. Without the knowledge that one is at risk one is unlikely to contemplate changing behaviour. Yet, surprisingly few studies have focused discreetly on perceptions of cancer risk among the 'lay' public. There are a number of qualitative studies that consider risk perceptions but do so in the context of screening awareness and behaviour. Studies that had screening as their main focus were excluded from this review. These often examine the decisions about participating in the cervical screening programme (Armstrong 2005; Armstrong & Murphy 2008), for example among women who have had abnormal pap smear results (Kavanagh & Broom 1998; Bertram & Magnussen 2008). There are also a number of studies that have looked specifically at the views of minority ethnic groups (Chavez et al 1995; Cohen & Azaiza 2005, Ackerson, Pohl & Low 2008) Some compare views across socio-demographic groups. For example a recent study found that non-whites perceived themselves to be at lower risk than whites even when other important variables like behaviour were controlled (Orom et al 2010). The

authors attributed this to variations in perceptions of family history. Non-whites were less likely to believe that they had a family history of cancer. Breast cancer and mammography screening are also commonly studied, particularly amongst those judged to be from high risk families (Chalmers, Thomson & Degner 1996; d' Agincourt-Canning 2005; Bakos et al 2008) or those with an identified genetic susceptibility (Ryan & Skinner 1999). There are those that concentrated on individuals who have a heightened genetic risk of colorectal cancer (Harris, Treloar & Byles 1998; McAllister 2003). Other studies have tended to look at high risk groups like smokers (Lowry & Craven 1999; Marteau, Rana & Kubba 2002) or those from a particular minority ethnic groups or migrant population that are at a heightened risk by virtue of their social status (Lanz et al 1994; Morgan, Park & Cortes 1995; Mishra, Aoulua & Hubbell 2000; Allen et al 2007)

3.4.3 The lay view of risk

Those few studies that did examine perceptions of risk among the lay public present an understanding of risk that is variable. Humpel and Jones (2004) found that most women over-estimated their risk of breast cancer. Robertson (2000) similarly found that the risk of breast cancer was over-estimated and that women reported that they felt an 'inevitability' about breast cancer. Perceptions of risk were fluid and that explanatory models changed in light of new information. Using tangible examples to inform beliefs about health was also documented by Katapodi et al (2005), who introduced the 'availability heuristic'. Heuristics are information shortcuts and, in the context of health, facilitate the development of health belief systems. The availability heuristic draws on data which is most convenient to access, like family experience rather than information from expert sources (Tversky and Kahneman 1981). Katapodi and colleagues suggested that the women involved in their study of breast cancer risk had used heuristics to develop a 'stereotype' of a high-risk individual. They then compared themselves with the stereotype and made their risk judgement about themselves accordingly. Most believed that they were at low risk because family history was a key feature of the stereotype. Their description of the stereotype is akin to the candidacy element of lay epidemiology, and like candidacy the women in this study gave examples of the stereotype failing. Although they concluded that all the women went through a

similar process to arrive at their individual risk assessment as Davison reported of candidacy, what is less clear is the universality of the stereotype. The universality of the coronary candidate was fundamental for lay epidemiology.

Risk was similarly underestimated in studies of colorectal cancer (Robb, Miles & Wardle 2004, 2007; Hay, Coups & Ford 2006). Robb, Miles and Wardle (2004) found that perceived risk of colorectal cancer was higher among those with a family history of the disease, poorer self-reported health, higher levels of anxiety, the presence of bowel symptoms, smokers and the physically inactive. Men and older-age groups tended to under-estimate their risk. Similar conclusions were reached by Hay, Coups and Ford (2006), though the relationships between smoking and risk and gender and risk were not upheld. Bowel symptoms, anxiety and poor self-reported health were again associated with a higher perceived risk (Robb, Miles & Wardle 2007). The qualitative arm of this study however found that more than half of the participants believed that their risk was average. Diet was central to the risk estimate, though the authors concluded that family history is critical in any estimation of risk.

A more general exploration of health promotion and cancer prevention was undertaken by Goldman et al (2008). They studied a group of working class people who had been exposed to a health promotion programme in the workplace, and found that most did not think cancer. There was widespread acceptance of risk factors - smoking, diet, the use of sunbeds, and obesity were commonly reported. While smoking was the most common risk factor, good nutrition was seen as the key to cancer prevention. Food additives were thought to be especially hazardous. As in other studies stress was also thought to be a risk factor. Environmental factors like toxins, radiation, power lines and pollution were all introduced into interviews by participants. Environmental dangers posed by working conditions were also cited as risk factors. A widely held view was that '*cancer is in us or around us, waiting to happen*' (Goldman 2008:784). Genetics, though not linked with all health issues, were frequently mentioned in relation to cancer.

A recent thematic synthesis carried out by Lipworth et al (2010) reviewed the literature on perceptions of cancer risk. The review included 87 papers that dealt with risk perception among high-risk groups and screening across a range

of groups. The information is synthesised into eight categories: perceptions of risk, the process of risk perception, seeking control and taking responsibility, experiencing cancer directly, constructing risk temporally, embodying risk, identifying with risk and constructing risk in a social context. Although not all of the categories are relevant, it was clear that perceptions of risk are not straightforward. While many sought to control their risk by behaviour modification or screening, others found strategies that allowed risk to be denied (Murray & Turner 2004). Many of those with an increased genetic risk, downplayed the overall importance of the genetic component (Sanders et al 2003). Some reported struggling to reconcile the unavoidable nature of risk, and many were fatalistic.

The finding that had most in common with lay epidemiology was the construction of risk in a social context, and although the findings in this section refer in part to relationships with health professionals, they include one study that considered the community experience of cancer (Salant & Gehlert 2008). Salant and Gehlert's study of African-American women drew on the ideas embodied in lay epidemiology. They conducted a series of focus groups and were particularly interested in the 'community' response to breast cancer risk. They found that participants evoked memories of a nostalgic time where risk was reduced because life was thought to be 'purer'. Participants emphasised the chemical aetiology of cancer, including pesticides. Stress was also thought to be major risk factor for breast cancer. Perceptions of candidacy were mixed though the major elements inherent in breast cancer candidacy were hereditary factors, poor lifestyle and age - though both older and younger women were identified as candidates. They did not find a precise model of causality or candidacy. Many participants reported that they gave no consideration to breast cancer unless they were confronted with it but that perceptions of risk are integral to their community's feeling of victimization.

Lipworth and colleagues (2010) concluded that what many of the studies included in their review had in common, was the assumption that if lay beliefs do not match those of health professionals, then the public are ignorant. The review recommended that the many factors that shape perceptions of risk should be taken into account including social, personal and psychological factors. Lipworth's synthesis is the only review available that brings together

literature on perceptions of cancer risk factors. This method of qualitative synthesis attempts to pull together findings from disparate studies and present a single message (Dixon-Woods 2006). However, including 87 studies makes this a large qualitative review. Although they aimed to include a very wide range of studies the meaningfulness of the resultant data must be questioned. The variety in both the types of participants and the subjects under study means the conclusions lack depth. They identified gaps in the existing literature and confirmed that 'at risk' groups are most commonly the subjects of studies that seek to explore risk. There is scope therefore to consider the views of the 'ordinary' person in relation to risk.

3.4.4 Risks and Genetics

Genetic risk is an area of great importance in terms of cancer beliefs. Family history is frequently placed at the centre of risk assessments - either for others or oneself. Scientific advances that have resulted in the identification of cancer genes have clearly captured the public's imagination. Specific genes BRCA 1 and BRCA 2 have been linked with breast and ovarian cancer and genetic elements are also found in some colorectal cancers, prostate and testicular cancers. Introducing a series of papers entitled '*Public Understanding of Science*' in 1995, Macintyre predicted a future where people could be screened for a 'wide range of cancers'. The paper called for a '*scientific understanding of the public*' (Macintyre 1995:228), where professionals appreciate the public's sophistication in this issue, rather than assume that they are unable to correctly process this data. According to Macintyre, many of the important factors, like interpretations of chance and probability, are well understood and moreover, *that many studies of lay beliefs about health and illness show how embedded in British popular culture are ideas about the inheritability of diseases* (Macintyre 1995:228). While this may be true, there is also evidence that risk can be underestimated because of the assumptions about inheritability (Kapodi et al 2005). In reality familial links explain only a small part of the risk. Further, the folly of assuming that lay and expert models of genetic risk are similar is demonstrated by Parsons and Atkinson (1992). In their seminal study of perceptions of risk among families with Duchenne Muscular Dystrophy they found that the women they interviewed often misinterpreted the risk information given to them, which in turn had influenced their reproductive decisions. This tied in with Gifford's (1986)

assertion that while for the epidemiologist the calculation of risk is an objective, technical process, but for the lay person it is a subjective, lived experience drawing on many different types of information. As Blaxter (1999) cautioned:

“there is a considerable risk in the assumption that we are all talking about the same thing” (Blaxter, 1999: 23).

Irrespective of the difficulties associated with genetics and cancer, it is an area that is receiving increased attention. Although the great majority of cancers have no genetic element, significant efforts have been made to raise awareness of cancer genetics. Piniewski-Bond et al (2003) evaluated a widespread advertising campaign to raise awareness of the cancer and genetics. They found that around 40,000 households had been aware of the campaign and around 15,000 had changed their views as a result. Although the authors conclude that the campaign served to eradicate myths about cancer genetics, much of the work that has been done reports that this is an area that is poorly understood. Of the 87 papers included in the thematic synthesis by Lipworth and colleagues, 23 dealt directly with ‘cancer families’. The location of a gene for breast cancer has led to a substantial amount of work which explores the perceived risks of women with a family history of breast and or ovarian cancer (Chalmers et al 1996; McAllister et al 1998; Ryan & Skinner 1999; Werner-Lin 2007). Also of colorectal cancer (Jacobs 2002, Harris, Treloar and Byles 1998). One concept introduced by Lipworth and colleagues is that of ‘liminality’ (Lipworth 2010), where those from at- risk families describe a sense where they are neither sufferers nor disease free. There is an important distinction to be made between those cancers where a ‘gene’ can be isolated and tested for, others where there may be a hereditary element, like prostate cancer, and those where there is no link. Macintyre claimed that the public understanding of genetics and disease is embedded in our society but the difficulty is that it may be that it is too embedded. Most of the studies already included here reported that people believe there to be a strong hereditary element in cancer, and as Kerr et al (1998) suggested, people falsely estimate their genetic risk. It is perhaps not surprising that those with a greater number of affected relatives believe themselves to have a higher risk (Beebe-Dimmer 2004).

3.4.5 Cancer risk models

The discovery of cancer genes and the rise in importance of risk has driven the development of cancer risk models. The result has been a burgeoning literature in this area (Freedman 2005) and a number of models that calculate risk. The National Cancer Institute in the US devotes a website to the calculation and estimation of risk⁸. Much of the literature in this area has focused on the understanding of risk and the most appropriate means of imparting such information. Han and colleagues (2007, 2009a, 2009b) have been prolific commentators in this area and have produced a series of papers that explore participants' views about and understanding of risk models, many of which were being promoted by the US National Cancer Institute. Much of Han's work considered the preferences for the presentation of risk information and models but concluded that risk could be interpreted in many different ways.

3.4.6 Risk and Cause: a semantic distinction?

While risk may be open to interpretation, it does refer to a prospective rather than retrospective judgement. Risk is probabilistic in nature and as Gabe (1995) posited, while it was once a neutral term, it has become almost wholly negative. The language of risk is important. All of the studies on awareness have asked individuals to comment on associations between risk factors and cancer, not causal relationships. Retrospective candidacy refers to perceived causal relationships - obesity caused the CHD event. Davison admitted that candidacy is less powerful when making future risk assessments.

There are few studies that discuss causality and cancer amongst the lay public. Some, like Blaxter's study, had health generally rather than cancer specifically as its focus (Blaxter 1982). Where there is a larger literature is the area of 'causal attribution'. These studies employ psychological concepts, like Health Locus of Control (Wallaston 1976) to gain an understanding of people's health beliefs, particularly about aetiology. Typically studies of causal attribution take cancer patients and survivors as their sample and ask them to propose the reason for the development of their disease (Faller Schilling & Lang 1995; Kohli 1998; Stewart et al 2001a, 2001b; Arman et al 2006; Costanzo et al 2005). Many

⁸ http://riskfactor.cancer.gov/cancer_risk_prediction/

of these studies have found that the importance of behavioural factors is underestimated (Maskarinec et al 2001) and typically that cancer patients are less certain about causality than non-patients (Linn, Linn and Stein 1982).

3.5 Cancer ethnography

Most of the studies outlined in the first section on cancer awareness among the general public deployed large questionnaire cross-sectional studies. Those studies in the previous section on perceptions of cancer risk highlighted the complexity of beliefs about cancer. Few studies have set out to capture the views of the lay population about what causes cancer, particularly in the UK and USA (Dein 2004). There have been a number of studies that have looked specifically at the understanding of cancer among various ethnic groups, most notably in the USA. Dein's review of this literature suggested that the majority of the groups studied have very little biomedical knowledge about cancer but they do have firmly held beliefs, many of which are heavily influenced by God and fate. One study of particular relevance to the west of Scotland that also explored beliefs about cancer in a cultural minority group was Scanlon et al's (2006) ethnographic study that compared Irish and white British people. A series of focus group discussions took place in Glasgow, Manchester and London among first, second and third generation Irish individuals and the indigenous white British population. They found few differences between the Irish and British participants and concluded that neither group had a particularly clear understanding of cancer. The majority saw cancer as a single disease that affected different parts of the body, though distinctions were made between good and bad cancers. Good cancers were those perceived to be curable. Participants also felt that some cancers could be "hidden" or "silent", and the sufferer may not know they have the disease. This unpredictable nature of cancer emphasised the fear associated with the disease, a response that was keenly felt among the groups, irrespective of biomedical advances. Some believed that cancer merely required a trigger to set it off. Most participants held a complex model of causality and a series of factors were thought to be important, including lifestyle, family susceptibility, and the physical environment. Irish participants were more likely to believe that cancer could be the result of economic disadvantage. Many, particularly Irish participants, were sceptical about the influence of lifestyle factors, though interestingly they

believed that the traditional rural Irish way of life offered a protection, unlike their urban existence, which encouraged unhealthy lifestyles.

The emphasis on the importance of environmental factors is not novel. In an earlier paper, Balshem (1991) recounted her experience as a health professional undertaking a research project in Philadelphia in 1980. She had originally intended to discuss heart disease but, partly as a result of recent media interest in the idea of cancer ‘hot spots’ in Philadelphia, cancer became central to her analysis. As with earlier studies (Linn, Linn and Stein 1982) Balshem found that the participants in her study concentrated on external factors when seeking an explanation for cancer. Most common among them was environmental pollution, though both God’s will and fate were also commonly offered as explanations. Fate therefore was more important in many ways than lifestyle because although lifestyle can improve your chances of avoiding cancer, fate had the ultimate power. Balshem attributed the elevated position of fate to the failure of modern science to convince her study participants that it was able to provide answers. Participants in Balshem’s study bemoaned the fact that ‘everything causes cancer’. In this respect cancer is the disease equivalent of the boy who cried wolf; if everything causes cancer there is no certainty about anything causing it. Participants in Balshem’s study were therefore sceptical of the importance of lifestyle factors and much like Davison’s ‘Uncle Norman’ (Davison, Frankel & Davey Smith 1991), Balshem’s participants introduced the ‘Defiant Ancestor’ who had engaged in all the ‘wrong’ behaviours but remained disease free. While the original ‘Uncle Norman’ stereotype simply defied the odds by living to a ‘ripe old age’ in the context of smoking and drinking heavily, Balshem’s ancestors had an additional quality. The ancestors were described in moral terms. They were seen to work hard, not to dwell on disease and to have a positive attitude. Such features are similar to the respondents in Blaxter’s (1982) generational studies of mothers and daughters where work and ‘not giving in’ to disease were lauded.

3.6 Conclusion: What do people know about cancer?

This section on the understanding of cancer has highlighted a number of critical points. First, there are relatively few studies that deal with the understanding and awareness of cancer among the general public. Those that are available

tend to employ large scale quantitative methods that say little about the subtlety and complexity of beliefs. Awareness of cancer risk factors is variable. The risks of tobacco are universally accepted and sun exposure is also becoming widely recognised as a hazard. Other known risk factors are less well appreciated, typically the importance of physical activity and alcohol consumption. The public are attached to a number of 'mythic' risk factors, stress being principal among them. They also appear wedded to the importance of heredity across all cancer sites. Many introduce fate and God's will into explanations of causality. Perceptions of risk are similarly variable. Some studies report an underestimation of risk and many others find the opposite. Undoubtedly the level of media attention the cancer risk factor receives is key in shaping beliefs. This would explain both the success of the smoking message and the misconception about the links between breast cancer and age.

As the reliance on 'Gods will' as an explanation suggests, the lay public draws on more than biomedical explanations in reaching an understanding of cancer. The cultural experience of cancer is also important, as the following section demonstrates.

3.7 The culture of cancer

For Davison, candidacy represented a "cultural mechanism" that allowed an easy understanding of what heart disease meant. The coronary candidate is a familiar, axiomatic image. It is an image based on a heart which endures strain, one that has to work too hard. This pervasive metaphor, of the heart as a pump, fits neatly into the wider mechanistic metaphor dominant in the biomedical model. This picture is arguably simplistic but there is no doubt that it aids the widespread understanding of 'heart trouble', which was central to the power and legitimacy of candidacy.

Cancer is arguably less straightforward and is often thought of as the most feared of diseases. If lay epidemiology is to be applicable to cancer then the cultural position of cancer needs to be fully understood. The following section first considers one of the most influential pieces of writing about cancer, if not disease: Sontag's *Illness as Metaphor*. It then goes on to look at some of the metaphors associated with cancer. As Lupton (1994) argued, metaphors often

hint at the way in which a disease is viewed by wider society. The section also details the depiction of cancer in the popular press, before concluding with a comparison between cancer and heart disease, which is at the core of this thesis.

3.7.1 *Illness as metaphor: Sontag and cancer*

Much can be learned about the cultural position of cancer by exploring the metaphors associated with the disease. An obvious place to begin is Susan Sontag's 'Illness as Metaphor'. Published first in 1978, the essay dealt with Sontag's own experience of breast cancer, though arguably it went far beyond the conventional personal accounts of living with illness. Sontag drew on the experiences of fellow patients and observed interactions in clinics and concluded that cancer metaphors worsened the entire disease experience.

"As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralized by learning what disease they have." (Sontag 1978:7)

Sontag drew comparisons between Tuberculosis, the disease of the 19th century, and cancer, the scourge of the 20th century. She referred to both tuberculosis and cancer as 'master illnesses' because both held social, moral and political significance, but they were not indistinguishable. Unlike cancer, tuberculosis was romanticised and Sontag provides frequent examples of literary figures who have succumbed to 'consumption'. As Lupton (1994) summarised Sontag's representation of tuberculosis

"...a disease of romance and passion, a sign of 'inward-burning' or ardour, conceptualized as disintegration, transparency, hyper-activity alternating with elegant languidness, leading to a noble and often lyrical death' (Lupton 1994:58)

Conversely, cancer had nothing to redeem it. It is 'horror-filled', consuming the public-psyche with dread. Sontag analysed the way in which cancer had been portrayed in the second half of the twentieth century. Her overwhelming conclusion was that cancer could not escape the stigma associated with it:

"... treating cancer as no mere disease but a demonic enemy, make it not just a lethal disease but a shameful one." (Sontag 1978)

This shame, according to Sontag, rendered individuals reluctant to discuss potential symptoms. Consequently, they failed to seek help and were untreatable by the time they sought help. Sontag's solution is to purge cancer of its symbolism and to view it as a purely biological entity. In her later essay (Sontag 2001) Sontag adapted the original Illness metaphor to include AIDS. Here she highlighted the morality inherent in illness metaphors. Both cancer and AIDS are seen to be punishments for not behaving correctly, for being weak, yet reckless and choosing to take risks. Sontag's chief aim was to de-bunk the taboo and stigma. She believed that:

"The most truthful way of regarding illness - and the healthiest way of being ill - is one most purified of, most resistant to, metaphoric thinking" (Sontag 1978:3)

Though Sontag's motivation was clearly honourable, there are ironies inherent in her essays. She overestimates the ability of science and therefore medicine to be objective. Moreover, she too utilises metaphors liberally, for example, in the introduction:

"Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick."(Sontag 1978:3)

Sontag has been labelled naïve for suggesting that illness can be free of metaphor and more particularly for claiming that bio-medicine, itself riddled with, and reliant on, metaphor for meaning, can be objective. The mechanical metaphor for the body is central to biomedicine and is used by patients and physicians alike. Some of the metaphors are so well-established that Lupton questioned whether they are now 'dead metaphors'. Lupton (1994) showed that there are many examples of medical professionals relying on metaphors to explain illness to patients. While Lupton acknowledged Sontag's naivety, she also recognised Sontag's role in illustrating the function of metaphor. People make sense of illness through metaphor and Sontag was instrumental in the widespread acceptance of this fact.

Weiss (1997) paid homage to Sontag in a study that interviewed nurses, physicians and students about their views of cancer, heart disease and AIDS. The project asked participants to provide pictorial images of each disease. Like Sontag, Weiss was clear that cancer immediately evokes fear, is inextricably

linked with suffering, and only AIDS patients experience similar levels of stigma. Yet, she offered a more contemporary analysis of cancer metaphors and claimed that rather than being seen as the 'leprosy of modern times', as cancer once was, the accent has shifted to more 'heroic' metaphors of 'hope' and 'fighting spirit'. In the pictorial representations, Weiss claimed that heart disease is devoid of imagery. The imagery attached to cancer was undoubtedly familiar. Cancer eating the sufferer from within and eventually consuming the whole person was presented repeatedly. Interestingly, Weiss found little difference between lay and professional depictions.

Sontag is not without her critics. In a provocatively titled essay *'Who's afraid of Susan Sontag?',* Clow (2001) not only criticised Sontag for her naivety, but questioned the entire validity of her premise. Though Clow accepted that cancer is a disease that patients are fearful of, she challenged the depth of the stigma and the apparent shame associated with the disease. Sontag, and later Patterson (1987), cited the euphemisms present in obituaries and implied that this evidenced the reluctance to reveal cancer as a cause of death. Clow conducted a detailed examination of post-war obituaries. She concluded that obituaries were 'opaque', which proved nothing and, according to Clow, fewer than 15% of all obituaries specified a cause of death. Clow asserted that the presence of euphemisms simply confirms cancer. Such an admission however surely serves to strengthen Sontag's argument. Clow stated that rather than attempt to obscure cancer, health professionals sought to provide information about cancer on mass scale and, what is more, the public had an appetite for personal accounts of cancer in newspapers and magazines. Yet Toon's (2007) account of the public health movement in the United Kingdom before the Second World War reinforced Sontag's argument. Toon demonstrated that there was a reluctance to provide information about cancer, as it was assumed that information would only increase fear. A similar conclusion was reached by Patterson (1987) who believed that public enthusiasm for cancer information was the result of 'cancerphobia'. Clow cited a Gallup poll from 1940, where 98% of people did not see any shame attached to a cancer diagnosis. This challenged Sontag's assumption that a cancer diagnosis is inherently shameful. Clow believed that Sontag's sources have not been sufficiently scrutinised. Though Clow is generally supportive of Sontag's motives and accepted that *Illness as Metaphor* was

profoundly important she concluded that Sontag simply succeeded in ‘mythologising’ the very metaphors she set out to eliminate:

*“Despite her intellectual prowess, despite the tremendous power and importance of *Illness as Metaphor*, it turns out that some people are not afraid of Susan Sontag.” (Clow 2001;310)*

A further critique of Sontag was tendered by Coulehan (2003) who questioned the necessity of removing metaphor from the medical encounter and the illness experience. Coulehan used the example of the Navajo where narratives and metaphors are central to the traditional healing process.

3.7.2 Historical Perspectives

Sontag essentially initiated the debate about the culture of cancer. Ten years after Sontag, Patterson (1987) published *The Dread Disease: Cancer and Modern American Culture*, a cultural history of cancer since the 1880s. Patterson’s account was arguably more academic and evidenced than Sontag’s but both reached similar conclusions. Patterson’s work led to a flurry of social histories of cancer. Jasen (2002), Aronowitz (2001) and Moscucci (2010) all provide interesting accounts that offer clues to the origins of the metaphors that Sontag described as so pervasive.

3.7.3 Cancer Metaphors

“ ... cancer is a disease which has occasioned a constellation of metaphorical systems, largely due to its severity, mystery and evasion of medical solutions.” (Lupton 1994: 66)

Regardless of the legitimacy of Sontag’s interpretation of the stigmatising nature of cancer, there is little doubt about the pervasiveness of the metaphoric nature of the disease. As the above quote from Lupton suggests there are many metaphorical representations of cancer. Cancer itself is a metaphor, and reflects the image of a tumour with the protruding legs of a crab. Lupton traced the history of cancer metaphors and showed that even in medieval times cancer was seen as a ‘gnawing’ animal and as rot invading the body which destroyed sufferers from within. There are a number of variations on this theme that bring the metaphor up to date. Hawkins’ (1999) analysis of pathographies concluded that cancer is often presented as:

‘an alien intruder or invading enemy’ (Hawkins 1999:66)

Allied to this are the ubiquitous combative or militaristic metaphors that have become standard when describing cancer. ‘War on Cancer’ was declared by US President Richard Nixon in 1971 when he launched the National Cancer Act. The aim of the Act was to eradicate deaths from cancer and though there have been notable improvements in mortality since then, the war continues. In this context cancer becomes ‘the enemy’ - a label that invites a string of metaphors. If cancer is both a disease that comes ‘from within’ and the ‘enemy’, then the leap to combative metaphors seems logical. Moreover, Lupton proposed that the use of many of the metaphors in modern media aim to ‘simplify’ cancer and improve the public’s understanding of a complex disease. Yet the straightforward description of the reproduction of ‘rogue’ cancer cells is easily translated as irrational and disorderly. Portraying cancer as an irrational, out of control ‘entity’ is also common (Lupton 1994). Unlike other diseases, cancer is often assigned a personality, displaying a series of traits. Adjectives like devious, sneaky, evasive are all commonly used to characterise cancer (Balsheim 1991).

Herzlich and Pierret (1987) described cancer as ‘THE disease’ of the twentieth century:

“In our representations cancer is the specific illness of our society, the prototype of the ‘modern illness’, that has become the very embodiment of physical suffering for us.”(Herzlich & Pierret 1987:55)

Over a number of studies spanning 30 years Herzlich and Pierret collected the views of cancer patients. They reported that some participants in their studies denied the historical existence of cancer, while others believed that though cancer may have existed, it was labelled as something else. Despite the participants’ insistence on the modern nature of cancer, Herzlich and Pierret charted a long history of accounts of cancer. They cited very early use of the ‘eating away’ metaphor from Thomas Paynell in 1528 who wrote ‘a canker is a melanchoyle impostume, eatynge partes of the bodye’. Death from cancer was documented as early as 1666, when Anne of Austria was reported to have died of breast cancer. Causal links were first documented in Sir Percival Pott’s study of cancer among chimney sweeps in 1775.

Interest in cancer then waned during the Victorian era, when the focus was on what they termed ‘social scourges’ - small pox, syphilis and tuberculosis. Nevertheless the language of plague continued to be used in reference to cancer, and they provided the example of ‘drop like flies’. This, according to Herzlich and Pierret, explains entirely the fear that was synonymous with cancer. People were unsure about the origins of cancer and whether it was contagious. Herzlich and Pierrett reported that their interviewees talked about the contemporary ‘obsession’ with cancer. Many participants suggested that while at one time a symptom was recognised as innocuous, the modern way was to immediately assume that cancer was at its root. Cancer was so feared that some were reluctant to ‘speak its name’. It was this duality that led them to conclude that cancer inhabited both the modern and the archaic:

“If cancer, like all great diseases whose impact on the collective consciousness we have tried to retrace, is indeed a metaphor, it is infinitely richer than Susan Sontag would lead us to believe: it is a metaphor that merges the archaic with the modern version of illness; a metaphor that uncovers our relationship with today’s world and at the same time brings us face to face with our fragility as individuals.” (Herzlich & Pierret 1987:66)

3.7.4 Metaphors and the individual

It is in the realm of the individual that metaphors become problematic. Separating cancer from the cancer patient is awkward, particularly as cancer is often believed to come from ‘within’. There is ample scope then for the ‘evil’ to be associated with the patient as well as the disease. The consequence is the stigma and shame trailed by Sontag. Arriving at aetiological explanations for each cancer case raises issues of personal responsibility and Lupton proposed that such ponderings often have a moral tone. Lupton cited Pinell’s (1987) paper that collated data from letters written by cancer patients to the Department of Health in France, the Concertation Nationale Cancer. Pinell asserted that the fear surrounding cancer is disproportionate to the actual threat, and claimed that

“Cancer condenses all the characteristics of an unforgettable horrible death” (Pinnell 1987: 27)

Pinell found that most contributors were reluctant to take any personal responsibility for cancer, instead locating the cause outside of themselves. Environmental pollutants for example were often cited. However, the letters went beyond that and hinted that ‘disharmony’ caused cancer. As one respondent wrote:

“I am convinced that there will be no cancer in a better world”
(Pinell 1987: 32)

Pinell concluded that the ability to see oneself as an innocent victim of cancer was important to those writing the letters. Similar findings were reported in earlier studies that asked cancer patients to comment on the causes of cancer (Bard & Dyk 1956; Moses & Civaldi 1966; Linn, Linn & Stein 1982). All three studies found that patients tended to hold factors outside their control responsible for their illness. Some of those factors included over-work, early deprivation (Bard & Dyk 1956) heredity or poor medical care (Moses & Civaldi 1966). Linn, Linn and Stein’s study compared the views of cancer patients with non-cancer patients and found that cancer patients were less certain about the causes of cancer than those without cancer. Those with cancer were more likely to endorse heredity and “God’s Will”, so distancing themselves from responsibility (Linn, Linn & Stein 1982).

3.7.5 Moral Responsibility

All of the above studies capture the importance of moral responsibility in the modern discourse on cancer. Are people responsible for their own illness? Does anyone deserve cancer? These questions force a return to Herzlich & Pierett’s analysis that cancer is both modern and archaic. Lupton showed that as the major diseases have moved from widespread epidemics to individual diseases like cancer and coronary heart disease the determinants of health have moved from the social to the individual. The emphasis is on behaviour. Smoking is widely recognised as a significant risk factor for cancer. The stigma felt by smokers has been reported (Mackenzie et al 2009). Again, Sontag’s analysis is relevant because, irrespective of Clow’s questioning of the depth of shame, studies have clearly documented the stigma experienced by lung cancer sufferers (Chapple, Ziebland & McPherson 2004). Stigma is attributed to the ‘horrible’ nature of lung cancer, the perception that the disease is self-inflicted, and the

high death rate. The paper is littered with examples of moral judgements and references to the 'dirty' label associated with all cancers, not just lung cancers. Though some interviewees saw smoking as the most significant factor, others, especially those that had joined support groups introduced environmental factors as possibilities. This shows the need to absolve oneself of responsibility.

As well as the moral responsibility associated with the cause of disease, another significant component of the cancer narrative is 'hope' (Lupton 1994; Ehrenreich 2009). Current convention suggests that cancer patients should remain positive and fight back. Hawkins' (1999) analysis of pathographies presented numerous personal accounts of illness that document 'the fight' against cancer. Both patients and health professionals use militaristic metaphors frequently and clinicians report that the use of such terms provides an essential analogy for the course of treatment and the 'journey' that the patient is about to embark on. Yet, Hawkins claimed that in many of these pathographies the veiled inference is that cancer patients who do not possess sufficient quantities of the 'fighting spirit' ultimately have poorer outcomes.

3.8 Cancer and the media

The media influence our understanding and experience of disease (Lupton 1994; Philo 1999; Seale 2003). However, much of the available information should be treated with caution. MacDonald and Hoffman-Goetz (2002) found in their analysis of the accuracy of information presented in Canadian newspapers that only 7% of articles contained factually correct information. Many of the well-known metaphors already described can be found liberally cited in the media coverage of cancer. Clarke's (1986, 1992) studies of the depiction of cancer in magazines published in the United States echoed Sontag's original thesis and reported on the commonality of military metaphors when reporting cancer:

"Cancer is described as an evil, immoral predator." (Clarke 1992:108)

Even before Nixon declared war on cancer, Clarke unearthed militaristic metaphors and cancer 'fighters' in popular magazines. Reports showed that cancer, unlike other diseases, impacts on the whole person and that following a cancer diagnosis the sufferer's life is changed irrevocably. Some articles

discussed personality characteristics associated with cancer. Principal among them were “*hopeless, inadequate or somehow desperate people*” (Clarke 1992:108). Together with individual traits, Clarke showed that a wide range of potential causes are put forward in the magazines, including ‘chickens or viruses’, though the most common cause was smoking. Individual responsibility was at the forefront of all the pieces. Clarke concluded that personal behaviours rather than environmental factors were more likely to be held responsible for cancer. These findings were replicated in a Clarke’s later analysis of Canadian magazines printed in 2001 (Clarke & van Ameron 2008), and most of the articles suggested that people have the power to change their own health.

Seale (2001a, 2001b) carried out an analysis of the coverage of cancer in British and American Newspapers in one week in October 1999. He subsequently offered an analysis of both religious and sporting metaphors. Seale developed Sontag’s ideas that explored the moral connotations of cancer and suggested that cancer can be viewed as a form of divine punishment and is seen as a demonic enemy. He believed that religion might answer questions about cancer that biomedicine is unable to answer, primarily, who deserves cancer? He postulated therefore that much of the media coverage would include the religious status of cancer sufferers, particularly in the United States, arguably a more religious society. Despite this he found only a handful of references to the role of religion in the cancer sufferer’s life. Religious language was used and individuals alluded to blessings and miracles though Seale surmised that these terms unknowingly evoked religiosity. Seale claimed that recovery from cancer is assumed to be a personal responsibility and much of the language, rather than militaristic, simply conveys ‘struggle’. It was rare for reports to make direct causal links between faith and survival. Faith was more likely to be introduced into terminal cancer stories. Seale concluded his analysis on religion by suggesting that patients with cancer and their families appear to seek answers from biomedicine rather than religion, though he did propose that the increased interest in complementary medicine and what he described as ‘psychological’ thinking may have replaced religious thinking in contemporary secular societies.

As well as an analysis of religious content, Seale (2001a) also examined the data he gathered to explore sporting metaphors. Previous work by Clarke and Robinson (1999) focusing on testicular cancer found that sporting and military

metaphors were commonplace. Seale suggested that sport is a 'civil religion', which provides a means to demonstrate individual worth and triumph when faced with cancer. Seale drew parallels between militaristic imagery and sporting language. In sporting stories terms like fighting and winning were used and interestingly Seale pointed to the use of 'rounds' to describe stages of treatment, much like sporting heats or boxing bouts. Often the sporting pastimes of people with cancer were reported. Seale provided a number of examples of young women with breast cancer involved in mountain climbing. The analogy of reaching the top while also overcoming cancer was used and, according to Seale, sport facilitates the emphasis on the 'heroic' nature of the cancer struggle.

Clearly the treatment of cancer in the media will focus on what is newsworthy. Seale noted that the concentration is on cancer among younger people, and in particular tragic cases. The focus on younger people has been documented elsewhere. Henderson and Kitzinger (1999) have looked at the way that 'inherited breast cancer', linked with younger women, has been treated by the media. In their analysis of newspaper coverage in the years following the discovery of the BRCA1 and BRCA2 genes they found that genetic factors were the second most common risk factor mentioned in newspaper articles. This is in spite of the estimate that only around 10% of breast cancers are genetic. Nevertheless genetic breast cancers are often tragic stories, some involving prophylactic mastectomies. Clearly, emphasising the unusual helps consolidate the tragic representation of cancer. Clarke and Everest (2006) in their synthesis of data from magazines found that the exacerbation of fear was the most common theme in cancer stories, and that fear and cancer had become conflated. Fear was presented in a number of ways: the silent nature of cancer is stressed, so one can have cancer unknowingly, cancer is presented as being common and has so many risk factors that some suggest that 'everything causes cancer'. Clarke and Everest proposed that the ubiquity extends to individuals, which exudes the idea that everyone will eventually develop cancer. The presentation of cancer in this way accentuated the uncertainty that is synonymous with cancer. As Comaroff and Maguire's (1981) study of parents of children with leukaemia claimed, it is the uncertainty that families are most fearful of. Despite advances in treatment, a proportion, albeit small, of the

cancer puzzle remains unsolved. The unanswerable, by its very nature, assumes a mythic quality.

3.9 Cancer vs. heart disease

Davison's work on lay epidemiology was developed from data generated in a study about Coronary Heart Disease. Lay epidemiology shows the importance of social factors in the understanding of disease, which also includes the cultural context in which information flows. It is useful therefore to compare cancer and CHD, in cultural terms. Many of the studies already reviewed make direct comparisons between the diseases. As Sontag noted:

“the doctors also treated the cancer as if it were something more than an illness: It wasn't like having a heart attack there was a taboo about it” (Sontag 1978:101)

Clow (2001) also considered the disparity between cancer and heart disease. Death from heart disease epitomises a 'good death', one that is both quick and unexpected, while cancer is characterised as a slow, painful and agonising demise. NicGabhainn et al (1999) concluded that heart disease was feared less than cancer. Lupton (1994) claimed that heart disease was 'morally neutral' and that very often rather than relying on graphic metaphors we need only look to biomedicine for our understanding of heart disease. Arguably then, lay and professional views of heart disease are more attuned than they are for cancer. Moreover, the reductionist model of heart disease allows the sufferer to become separate from their disease, with the heart is viewed in its mechanical context. Cancer, however, permeates slowly from within:

“It begins in silence. In the beginning no one knows what is happening inside. Then it begins its course. Ruins you from the inside. Until it consumes everything.” (Weiss 1997:462)

Weiss concluded that metaphors for heart attacks were more pragmatic, and less emotionally loaded or sad as cancer metaphors. Similar findings are reported by Emslie, Hunt and Watt (2001a) in their study in the West of Scotland. The strength of the tragic in cancer metaphors may in part be explained by a lack of understanding. MacFarlane & Kelleher (2002) found that cancer was the only disease that could not be explained by the older adults in their study. Many of

the studies already detailed in this review (Balschem 1991; Weiss 1997; Scanlon et al 2006) have found that participants were surer of the causes of heart disease:

‘When they say heart attack I see fat ambulatory treatment, fat dishes, hamburger, cigarettes, gym, smoking, weak person, a machine in need of fixing, pump, heart transplant, explosion, plumbing, heart palpitation’ (Weiss 1997:467)

Heart disease, Davison found was often attended with humour (Davison, Frankel, & Davey Smith 1992). This is not echoed in any of the studies of cancer. What this brief comparison shows is that cancer and heart disease have very different meanings. This is likely to reflect the different ways in which the diseases are culturally framed.

3.10 Conclusion: culture of cancer

Much of the previous section has shown that cancer has a distinct cultural position. It is thought to be the ‘most feared’ disease, and even allowing for medical advances it continues to inhabit the terror ground. This terror and the associated uncertainty can be traced back to early experiences where a cancer diagnosis almost inevitably meant death. The manner of this death was always negative, characterised by a sudden shock or a long, painful demise. Early health promotion efforts hoped to demystify the disease but by offering only small amounts of information tended to exacerbate cancer’s negative image. Cancer is defined by shame and stigma and although this is perceived to be a somewhat old-fashioned view, modern media continues to emphasise fear and the stigma comes from the lack of hope or fight in the face of the disease. Any study of beliefs about cancer and how they are developed and refined needs to be mindful of the disease’s unique cultural position.

4. Aim & Research Questions

4.1 Aim

The study aims to explore beliefs about cancer and ascertain the utility of the ideas held within lay epidemiology in the formation of such beliefs

4.2 Research Questions

- What are typical views about cancer?
- Does lay epidemiology offer an aid to our understanding of beliefs about cancer and cancer risk?
- How important are personal, social, cultural, biomedical and environmental factors in the formulation of beliefs about cancer and cancer risk?
- Is there any notion of candidacy in relation to cancer?
- To what extent are anomalous deaths and unwarranted survivals employed in formulation of beliefs about cancer and cancer risk?
- Do lay explanations view cancer as a homogenous disease or multi-site and multi-causal?
- Are there differences between beliefs in deprived and affluent communities?

5. Methodological Considerations

5.1 Introduction

The aim of this study was to explore whether features of ‘lay epidemiology’ could be found in beliefs about and explanations of cancer. Access to rich, in-depth information was required. Moreover, the focus was not on cancer sufferers but on ‘ordinary’ views. Qualitative interviews provide an ideal vehicle for generating such data. A qualitative approach was proposed. However, ‘lay epidemiology’ is an already established theory and qualitative work, conventionally, seeks not to test theory but to uncover new findings. The methodological challenge for this study was to locate it within a qualitative paradigm despite this obvious departure, before selecting an appropriate research strategy. The following chapter outlines those deliberations and the process of finding a method to fit. More detail of the methodological design of the study appears in the following chapter on methodological design.

5.2 Background

Unlike quantitative theses, those embarking on qualitative studies are expected to provide detail of their ontological and epistemological persuasion (Silverman 2005). There are a number of ways to interpret this. It could point to the status of qualitative methods as the ‘poor relation’ in social sciences research and there is no doubt the method has struggled to gain credibility and acceptance. Alternatively, the requirement could be viewed in a more positive light. By asking students to grapple with a set of complex issues and ideas that deviate from the received view, the result is a thorough grounding in the theoretical underpinning of their work and the ability to use and defend their chosen method with confidence.

From its inception this study focused on the ‘lay’ voice. Despite modifications to the research questions in the early part of the study, the desire to locate and understand ‘ordinary’ views about cancer and how these were shaped remained constant. The aim was to build individual cancer narratives for each participant, detailing not only their current views but also to explore how and why they had arrived there. There was a need then for the ‘thick description’ (Geertz 1973)

captured by qualitative enquiry. Once heralded as the method that ‘reaches the parts others can’t reach’ (Pope & Mays 1995) a qualitative approach not only allows the access to in-depth material, but also more importantly for this study, sheds light on the ‘process’ as well as the ‘outcome’.

In the planning stages of the study the research question evolved to include the ideas found in an already established theory. By introducing the concepts found in lay epidemiology into the research questions, was the essence of this work hypothesis testing? Was this work largely deductive, therefore breaching a cardinal rule of qualitative research? This posed a serious challenge, initially, and there was concern that it would struggle to ‘fit’ philosophically, within a qualitative paradigm.

This chapter will look closely at the theoretical issues raised by this thesis, most notably the difficulty associated with combining qualitative research and existing theory. An understanding of the relationship between research and theory is considered before ‘theory’ itself is explored. Epistemology, ontology and methodology are key to understanding the dominant paradigms and each will be discussed. The discussion will conclude by locating the study in an appropriate theoretical tradition (or traditions).

5.3 Placing theory in the context of research

Traditionally, the separation is drawn between deductive and inductive theory. It could be argued that deductive theory, the central tenet of quantitative study, is being employed here rather than the inductive theory associated with a qualitative approach. The distinction is thought to be crucial and lies at the heart of the quantitative/qualitative debate. Deductive logic follows a sequential loop where theory leads to the development of a hypothesis that can be tested in experimental conditions; the outcome (either the verification or falsification of the hypothesis) is then fed back into the theory. The contrary position is inductive reasoning. In an inductive approach theory is the end result rather than the starting point. Conventionally then, deductive theory is associated with quantitative work and inductive with qualitative work. Bryman (2004) however reminds us that the distinctions are not always straightforward. Often, the boundaries are blurred and features of each can be found in the

opposing tradition. For example, Bryman highlighted that induction often takes place at the end of a deductive cycle by adding to the body of theory. Moreover, in a largely inductive approach, deduction can be found and is in fact a central feature of grounded theory (Glasser & Strauss 1967) where an 'iterative' relationship between data and theory is encouraged from the outset. Silverman (2005, 2001) has argued that qualitative researchers frequently engage in testing theories, which demonstrates the maturity of the strategy.

With this in mind then it is clear that the introduction of 'theory' in the early stages of this study does not immediately obviate its place within a qualitative paradigm. Further reflection on the research questions shows that the emphasis is not on hypothesis testing but rather on the exploration of the utility of the ideas found in lay epidemiology when applied to cancer, rather than deducing that lay epidemiology can, (or can't) explain beliefs about cancer.

5.4 Paradigms: 'The complexity deepens the more you delve'

In any deliberation of theories that underpin research, their complexity is instantly evident. This is not helped by authors' use of a wide range of jargonistic terms and the frequent overlap between descriptions of 'paradigms', 'traditions' and 'strategies'. For the purposes of this discussion it is helpful to organise these components in a hierarchy beginning first with a description of paradigms followed by their constituent parts, namely epistemology and ontology. The major traditions within each paradigm will then be described before specific research strategies are discussed.

Within texts on the philosophy of science and social science, paradigms feature strongly. Kuhn (1970) referred to a paradigm as an epistemological and ontological view of the world, the 'model' in which science is located. It is a common set of principles that guide enquiry and offer solutions to problems. Although Kuhn believed that social sciences were in a pre-paradigmatic phase because there was, as yet, no dominant set of guiding principles it is common for the social sciences to be described in paradigmatic terms. Like Kuhn, Denzin & Lincoln (2000) describe paradigms as 'a basic set of beliefs that guide actions'. They comprise three components: epistemology, ontology and methodology and

each component asks a specific question. Firstly, epistemology questions the nature of knowledge and what can be known. Ontology is concerned with reality, and questions the nature of reality and finally methodology offers guidelines on how to gain knowledge about that reality.

5.5 Epistemology: realism vs. interpretivism

There are two main epistemological standpoints - realism and interpretivism. Realism, which is akin to positivism, asserts that social science should emulate natural science and arrive at 'reality' where a 'truth' can be found. The process is bound by already agreed and appropriate strategies of investigation and the investigated and investigator represent discrete entities. Studies within realism strip away bias, and results can be replicated and widely applied. As with natural science, the method of inquiry is experimental. Critics label it 'naïve' realism because it fails to acknowledge the importance of 'structure' and social reality. To counteract this Bhaskar (1978) offered critical realism, which trusts that a tangible reality exists but there is more than one way of knowing it. Further, critical realism allows for intangible 'mechanisms' whose effects can be observed (for example racism) rather than 'knowing' only what can be directly observed.

Interpretivism posits an alternative epistemological view. It distinguishes between the social and the natural world and rejects the possibility of studying the social world in the received 'scientific' view. The tradition embodies the Weberian notion of *Verstehen*, which loosely translated means 'understanding' or 'appreciation' (Tucker 1965). Weber believed that through 'interpretation' it was possible to offer explanations for social phenomena, and to extend the scientific observation of realism. Similarly, hermeneutics and phenomenology concern themselves with the study of how individuals make sense of their world. Schutz (1967) insisted that an alternative epistemological tradition is required because quite simply, social reality means something to humans, and their actions are inseparable from their interpretation of 'reality'. Phenomenology then, attempts to see the world from the point of view of those being studied. Symbolic interactionism too has been placed within an interpretive paradigm, although its place there is contested (Denzin 1989). Embedded within symbolic

interactionism is the notion that our sense of self is derived from the way in which others see us.

5.6 Ontology: objectivism vs. constructionism

Objectivism views social phenomena as ‘facts’ that exist separately from individuals or society. For example, Bryman (2004) asserted that organisations or culture are afforded tangible properties, which hold within them distinct features that ensure their continuation. The opposing view, constructionism, sees phenomena as the creation of individuals and society, which are constantly changing and shifting. Even those of a constructionist persuasion acknowledge that there is some ‘reality’ because the extreme of this position is untenable, although some would argue that the way we reach an understanding of such phenomena is in itself socially constructed. Such constructions will vary across time and place and in different cultures and communities.

Intuitively, an exploration of lay views about cancer fits within the interpretivist/ constructionist paradigm. In the broadest sense the research focus is on beliefs about health. Health, however, is an abstract term, which is difficult to scrutinise in scientific conditions, particularly because the meaning ascribed to it varies widely. In the 21st century, in the developed world, health has come to mean more than simply the absence of disease, and has adapted to incorporate new ways of thinking and developments. Further, health is likely to mean different things to different individuals and communities, both at different historical time points and within different cultures. In this study, comparisons are made between views in affluent and deprived communities in Glasgow. Observational studies show stark differences in mortality and morbidity between the two and it may be that the experience and meaning ascribed to ‘health’ will be different.

5.7 Quantitative/Qualitative divide.

Positivism is the paradigm associated with quantitative research and the answers to questions of epistemology and ontology appear relatively simple. Crudely, within positivism, it is accepted that there is a single reality that can be studied (ontology), that the researcher can do so objectively, free of value

(epistemology) and that there are established techniques or strategies that allow the pertinent questions to be answered (methodology). It is worth noting that Guba and Lincoln (2000) suggested that although the term ‘qualitative’ is often used as the umbrella term for a number of paradigms, they prefer its use to be confined to a description of methods. They believed that qualitative methods have been and continue to be employed in a positivist framework.

5.8 Theoretical traditions

Denzin and Lincoln (2000), when charting the history of qualitative research, described five main epochs of qualitative method. This provides a helpful way of contextualising the method and shows how it has evolved into its present guise. They began with the traditional period, which started around 1900 and culminated with post-modernism from 1990 onwards. The most industrious period, from 1950-70, was a moment of “creative ferment” that saw the emergence of the qualitative enquiry proper. A number of interpretive theories, including ethnomethodology, phenomenology, and critical theory all emerged at this time. This period then gave way to a time dominated by “*blurred genres where researchers had a full complement of paradigms, methods and strategies to employ in their research*” (Denzin & Lincoln 2000:9). All of the major methodological movements were by now established. In recent times, methodology has a postmodernist feel, and the critical may describe it as a methodological ‘free for all’.

Despite this ‘full complement’, Guba & Lincoln (2000) claimed that four basic inquiry paradigms inform everything else: positivism, postpositivism, critical theory and constructivism. Positivism and postpositivism, are seen as falling within the tradition of realism/objectivism, while critical theory and constructivism inhabit the interpretive/constructionist paradigm.

Denzin and Lincoln (2000) proposed that the research process should follow a standard pattern. First, researchers should place themselves within a paradigm, decide upon epistemology and ontology, and this would in turn prescribe the methodology. The research process should flow from there:

“ All research is interpretive, guided by a set of beliefs and feelings about the world and how it should be understood and studied. Some of these beliefs may be taken for granted, only assumed; others are highly problematic and controversial. However, each interpretive paradigm makes particular demands on the researcher, including the questions that are asked and the interpretations that are brought to them.” (Denzin & Lincoln 2000:13)

More recently there has been a shift in emphasis. Qualitative research is becoming more pragmatic. Silverman (2005) and Bryman (2004) for example, advocate a process which begins with the research question. The starting point should not be the paradigm. Methods are chosen because of their suitability in answering the question. Of course, it is unlikely that researchers who feel at home in one tradition would ask ‘incongruous’ questions. So, the researchers’ beliefs are likely to colour research projects from the outset. In itself, this reflection is important philosophically as it demonstrates the centrality of the researcher to the process.

The newfound pragmatism negates the necessity of being overly concerned with epistemological and ontological questions. However, it is naive to assume research studies are themselves conducted in value free vacuums. The focus on the ‘lay’ and not scientific view of cancer in itself hints at the rejection of realism. Giving equal weight to a variety of different lay views demonstrates an acceptance of a constructivist ontology where no single truth is sought, or even required. However, the duality of positions in realism and interpretivism or objectivism and constructionsism fails to capture the spectrum of positions between the polarised extremes. In reality research is more likely to exist somewhere in the middle. Hammersley’s (1992) ‘subtle’ realism offers an attractive alternative. It could be described as a common sense approach, which allows that, while there is no ‘certainty’ in knowledge, there are areas of knowledge that can be judged true based on being both credible and plausible. Yet, subtle realism also allows for multiple truths or realities, giving comfort to social constructionists. Hammersley states that the job of social research is not, as positivism or realism would suggest, to reproduce reality but to represent a credible and plausible version of it. Nevertheless, subtle realism remains within the positivist school and its adoption could be seen as imposing a positivist framework on an essentially interpretive endeavour.

Social constructionism chimes in with the basis of this study in an important way, namely that it acknowledges that the result of research is a construct of the interaction between the researcher and the researched. Not the production of independent data waiting to be unearthed. It is data-generation rather than collection (Barbour 2003) with the researcher playing a central role. Ordinary views about cancer will not be articulated in precise lay epidemiology concepts, though clues to the utility of the concept will emerge in the individual narratives told throughout the interviews. These were not however narratives waiting to be told, as they might be for cancer patients. Indeed, placing their ideas in the context of lay epidemiology was not natural for them; it was a construct placed upon them. Moreover the impact of social factors on these views is clearly understood.

5.9 An embarrassment of choices

As well as the epistemological and ontological standpoint the actual research strategy employed is of obvious importance. A number of strategies were considered but it was clear that no one strategy coincided precisely with the research question. Phenomenology, for example, aims to capture the essence of lived experiences and is a method that is useful when researching the impact of an illness or particular event on a patient's life. So, if this study were looking specifically at the 'lived experience' of cancer, a phenomenological approach may have been apt. This study is subtly different because it did not aim to explore a particular experience, instead it sought to explore belief frameworks about cancer among the 'ordinary' public. Ethnography too, offered a possible strategy but crucially traditional ethnography demands some time immersed in 'the field' observing the reality of communities. From this perspective ethnography is often regarded as descriptive rather than interpretive, and would therefore have represented a significant paradigmatic shift for this study. The distinction between data excavation and data construction needs to be made and both phenomenology and ethnography could be viewed as excavation tools. Though not without flaws, grounded theory provides a useful template for analysis and this study is therefore influenced by, but does not claim to follow, a pure grounded theory approach.

5.10 Grounded theory

Glaser & Strauss (1965, 1967) developed the 'grounded theory approach' during their studies of the end of life during the 1960s. It was a direct response to the dominance of quantitative methods, as Charmaz comments:

“ In the Discovery of Grounded Theory, Barney G Glasser and Anselm L Strauss (1967) set forth a powerful rhetoric of change from the quantitative cannon to legitimize qualitative enquiry.” (Charmaz K 2009:128)

Grounded theory offered a systematic method for carrying out qualitative research. Originally grounded theory featured a number of crucial tenets: coding, memo-writing, constant comparative analysis and theoretical sampling. At its heart was the notion that the theory should emerge from the data, and that analysis should be iterative with emergent theories being fed back into the data collection process. Thus making additions and refinements to the questions and seeking out specific participants to test emergent themes. The theory has altered since its development and although Glaser (1978, 1992) largely maintained his original position, Strauss diversified and through work with Corbin concentrated specifically on grounded theory as an analytical tool (Strauss & Corbin 1990). While Strauss has urged researchers to take a smorgasbord approach to grounded theory, his description remains prescriptive as he insists on the inclusion of most of the original elements.

Grounded theory is not without its critics. A common problem associated with the method is the idea that researchers should enter the field of study with no preconceived ideas; that they approach it as a 'blank canvas'. Any theory emerging does so naturally rather than as a result of the researcher's previous orientation. Silverman (2001) has rejected this notion and cautioned against data gathering without any analytic basis. Bryman (2004) too questioned the intelligence of such a position and suggested that to wipe clean any prior knowledge and learning does research a disservice. Pure grounded theory however is both impractical and almost impossible to achieve, and as Barbour (2003) points out

*“ We (researchers) have some notion, even at the outset, of what our data are likely to look like and what we intend to do with it”
(Barbour 2003:1022)*

Despite this, grounded theory has recently become synonymous with ‘quality’ in qualitative research. Barbour (2003) warned of the technical essentialism associated with the acceptability of qualitative research. There is a sense that in seeking to make qualitative work fit in with a received view, it may lose its essence. So although, as Barbour (2001) reflected that grounded theory has become ‘an approving bumper sticker’ (Bryman & Burgess 1994), the analytic tool - constant comparison of data - intuitively ‘fitted’ here. More attention is paid to the analytic methods in the following chapter.

5.11 Chapter Summary

Placing this study neatly within a single research paradigm was initially problematic. The aims and objectives were clear but it was not always obvious that it neatly fitted any of the conventional ‘perspectives’. Instead, it was important to first locate the study in an epistemological and ontological paradigm. Seeking views about cancer and the utility of lay epidemiology required an interpretation of the stories told and views offered rather than the uncovering of one true story. Moreover the stories and interpretations were constructed via the interaction between the researcher and respondent. It seemed then that this study naturally fell into the social constructionist paradigm, despite the difficulties with this position. An extreme constructionist view necessitates that all knowledge is ‘new’, with nothing to build on. As Morse warned:

“The practice of some qualitative researchers of refusing to consult the literature and refusing to place the theory within the context of the work that has already been published is a serious problem. It results in a plethora of small and competing contributions to the literature. These contributions are not additive, they do not build on what has been published before; thus, qualitative inquiry as a discipline makes only a minor impact and has trouble demonstrating its contribution to science.” (Morse 2000:715)

Primarily this study was pursued with pragmatism. It accepts Strauss' (Strauss & Corbin 1990) invitation to adopt a smorgasbord approach when considering methods. A discussion of the methodological design and process follows.

6. Methodological Design

This chapter is divided into two sections. The first, design, outlines the research plan, while the second outlines the research process. Both include descriptions of sampling, methodological technique, namely interviewing, and finally, analysis.

6.1 Sampling Strategy

6.1.1 Design

A number of sampling strategies are available to the qualitative researcher. These are principally theoretical or purposive sampling, though convenience sampling and snowballing may also be employed. The validity of relying on convenience techniques has been questioned (Richie & Lewis 2003). The chosen strategy should reflect the aims of the study and the degree of prescription about the characteristics of the sample will reflect both the strategy adopted and the research questions.

Theoretical and purposive sampling strategies are often set out as two distinct approaches but Mason (1996) regards them as more or less identical. A fluid approach to sampling is assumed and it aims to deal with gaps or address interesting findings that emerge early in the research process. The tool is closely aligned to Glaser and Strauss' Grounded Theory (1967). They outlined it as a method:

“whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges.” (Glaser & Strauss 1967 p45)

Purposive sampling similarly targets respondents with certain characteristics but these are generally fixed from the study's outset and a sampling frame, which allocates the sample population to appropriate groupings, is produced to inform the strategy. While neither strategy claims to be representative an attempt has been made to access a wide range of views. In discussing the approaches Lewis (2003) suggested:

“Both rely on the use of prescribed selection criteria, although prescription takes place at different stages of the research.” (Lewis 2003:82)

The strategy adopted in this study was more purposive than theoretical in the Glaser and Strauss sense. The aim of this study, to obtain lay views and beliefs about cancer, was clear. Shaw (2002) alerted researchers to the difficulties associated with studies that claim to report a ‘lay’ view. Often quasi-professional language is adopted by patients and Shaw argued that many patients take on expert role in the management of their illness. The result is a viewpoint not typically associated with the laity. Cancer patients were unlikely to offer a genuinely lay view and as such were excluded from this study. Carers, it could equally be argued, may be experts and certainly many are likely to ‘live’ through the illness with the patient. Deciding whether carers’ views were sufficiently lay was a significant challenge for this study. Ultimately, it was judged that the common incidence and prevalence of cancer may make a sample ‘unaffected’ by cancer difficult to recruit. Moreover, if carers were to be excluded, a definition of ‘carer’ would have to be reached. Such a definition would have necessitated arbitrary judgements to be made about ‘closeness’ and as Chapter 7 shows closeness and relationships within families are not always logical. Those who regarded themselves as carers were included and on reflection, in the context of a high cancer incidence and prevalence, their inclusion may be more likely to represent an ‘ordinary’ view than those unaffected by cancer.

The description of the lay epidemiology concept in Chapter 2 shows that information to populate health belief models is gathered from many sources. Among them are wider community networks. The original ethnography carried out by Davison, Frankel and Davey Smith (1991) took place in three communities in South Wales. Salant and Gehlert (2008) in their study of lay epidemiology and breast cancer risk suggested that arriving at a definition of community is challenging. Ordinarily, community simply applies to a geographical boundary that is drawn to ascertain socio-economic and structural characteristics; often to decide need and allocate resources. This accurate but administrative definition tells little of what it means to live in a community. Notwithstanding the difficulties in definition, if community is important in ordinary views, the sampling strategy had to attempt to accommodate a community perspective. In

Glasgow, a city now infamous for the striking health gradients between affluent and deprived, it was apt to reflect both constituencies. Indeed, as the background and introduction in Chapter 1 outlined, the administrative boundaries have allowed the identification of very different cancer experiences between the affluent and the deprived.

There were therefore two main criteria to consider when sampling. First, that cancer patients should be excluded and second, that the views from affluent and deprived communities should be accessed. The sampling frame and strategy were relatively straightforward. However, the strategy represented something of a departure from usual approaches. While theoretical and purposive strategies seek to ensure that a range of views and experiences are accessed, this study did not begin from this starting point. Instead it aimed to uncover a variety of phenomena that contributed to 'ordinary' beliefs about cancer. What was sought was the ordinary view and in that respect the study did not seek to fill quotas.

Samples in qualitative studies are typically small. There are both theoretical and practical reasons for this. Qualitative data does not aim to generalise findings to a wider population, so large numbers are not required to ensure validity. In addition, qualitative research is data heavy and labour intensive, particularly if approached conscientiously (Richie, Lewis and Elam 2003). This study aimed to carry out 40 interviews, 20 in each community. It was judged that this number would allow a meaningful comparison between communities.

6.1.2 Process

The first step in the sampling process was to select the communities in Glasgow. The communities were selected primarily because of their health statistics. Bearsden and Milngavie are suburbs of Glasgow and are locally recognised as affluent communities. The towns form part of the East Dunbartonshire local government district, which was recently voted one of the best places to live in Scotland⁹. Life expectancy for the area is high¹⁰ and the health behaviour profile reflects that of other affluent areas. Conversely, Glasgow's east end has become synonymous with poor health. It is an area of high unemployment and

9 http://news.bbc.co.uk/1/hi/scotland/north_east/8421193.stm

10 GGC Joint Health Protection Plan 2010-2012

experiences the multifarious problems associated with socioeconomic disadvantage. The study initially targeted Shettleston, primarily because of the ‘Shettleston man’¹¹ media coverage, but expanded to other areas of Glasgow’s east end.

Recruiting participants from general practice populations was considered initially. It was planned that letters would be distributed to a random sample of general practice patients in both communities. The distribution of patient information would take place over a discreet time period. For example, every fifth patient attending their doctor, over the course of a specified time period, who met the inclusion criteria, would receive a letter of invitation. A number of problems were anticipated with this method. First, inviting patients, via their GP practice, to participate in a study about cancer could potentially cause confusion and distress. Second, it was thought likely that those who attended their general practice more than once over the defined time period might receive multiple invitations. Even misconstrued coercion was best avoided. Finally, in light of Shaw’s (2002) caution, it was thought that selecting ‘patients’ from a healthcare setting would compromise the lay and ordinary nature of the study.

To satisfy the aims of the study it was decided that volunteers should be sought from community organisations. Health-related groups were excluded, again in an attempt to avoid the ‘lay-expert’ health view. A variety of community organisations and leisure clubs were contacted in each community. This was done both by email and a more conventional mail-shot. In Bearsden/Milngavie many local organisations were listed on the East Dunbartonshire Council’s website. The Community Health Partnership in Glasgow’s east end keep a database of community organisations. Due to data protection guidelines, they were unable to share the data base but agreed to contact the groups on the study’s behalf. Local political parties, community councils, tenants’ organisations and churches of all faiths in each area were also approached. Posters were displayed in libraries and community centres. A full list of the organisations contacted is available in Appendix 2.

11 http://news.bbc.co.uk/1/hi/scotland/glasgow_and_west/7227953.stm

6.2 Data Generation

6.2.1 Design

Like sampling strategies, there are a number of strategies available within the cannon of qualitative methods to generate data. Observation methods were quickly dismissed because it was felt that these would not provide the data required to meet the aims of this study. Consideration therefore needed to be given to whether focus groups or interviews would best suit the purpose. Focus groups are ideal for generating a certain type of data that draws on the interaction between group members (Kitzinger and Barbour 1999). Although an argument could have been made for using focus groups for this study because of its community perspective, there was the danger that the discussions could simply have become a trade in cancer anecdotes. Rather, this study hoped to generate rich data that encapsulated thoughts and beliefs about cancer and in depth interviews provided the most likely vehicle for this. Moreover, the original lay epidemiology model as described by Davison and colleagues (1991) was derived from data generated during one-to-one interviews and it was felt apt to replicate this method, if useful comparisons were to be made.

Most qualitative research is carried out by some form of interview despite it being 'hard, creative, active work' (Mason 1996:67). Such popularity has meant that there are many texts available that offer hints on how to carry out interviews. For example, Kvale (1996) suggested that there are ten important skills that any qualitative researcher should possess and nine different types of questions. A more helpful summary was offered by Mason (1996) who recommended that qualitative interviews include the following 'core' features. Interviews should resemble an informal dialogue that is guided by themes or topics and crucially, there must be recognition that the product of the interview reflects a 'construction'. The ideal interviews therefore are what Burgess (1984) called 'conversations with purpose', though this 'touchy-feely' language may betray the complexity of good interviewing. The various skills associated with in-depth interviewing were summarised by Legard, Keegan and Ward (2003):

"First the ability of the researcher to listen is fundamental to the art of interviewing. The researcher must hear, digest and comprehend

the participant's answers in order how to decide to probe further. Second, good in-depth interviewing requires a clear, logical mind. The researcher needs to be able to think quickly to distil the essential points of what the participant is saying, exercise judgement about what to pursue, and simultaneously formulate the relevant question. Third, a good memory is an important attribute. It is often necessary to make a mental note of a point made earlier on by the participant and return to it at the judicious moment in the interview to seek further clarification or elaboration.” (Legard, Keegan & Ward 2003:142)

Given the repertoire of necessary skills, and the ability for participants either to clam up or ramble it is evident that unearthing helpful data is demanding. Not ‘getting at’ the required data is not the only problem associated with interviews. Bordieu (1977) argued that interviews are the least effective method because the information given by participants is a “public account” that tells interviewers what they want to hear or what participants are comfortable disclosing. Bordieu suggested observation methods be used to counteract this but such a method was not applicable in this study. Alternatively a series of interviews with the same cohort of participants may foster the emergence of ‘private accounts’ (Cornwell 1984). Though such an approach may have been beneficial in this study, it was dismissed on purely practical grounds.

6.2.2 Interview process

Semi-structured and unstructured formats are both used in qualitative interviews, although many suggest that even the most unstructured interviews will have some structured elements (Mason 1996; Collins 1998). Unstructured interviews generally begin with loosely focused questions. Subsequent questions and prompts are individually tailored in response to the interviewee’s answers. A level of structure may be employed to ensure a level of consistency throughout the interviews. The interview process in this study followed a largely unstructured approach but it also sought to ensure that the key concepts in lay epidemiology were sufficiently covered. A number of key ideas were introduced in each interview and the topic guide reflected this (Appendix 7). The concepts of risk estimation, candidacy, anomalous deaths and unwarranted survivals all required exploration in interviews. Lay epidemiology as a concept is relatively jargon-heavy so it was necessary to find a more familiar and informal language. This was done by first asking participants to talk about people they had known

who had had cancer. Participants' responses, in the form of narratives and anecdotes, provided the opportunity to probe further details and explore the impact of the experience of others. Participants were then asked to consider any apparent similarities between sufferers and reflect on the extent that they met with their ideas about 'who gets cancer'. It was this line of questioning that allowed the exploration of the notion of cancer candidacy. Such discussions also facilitated the discussion of anomalies. Prior to the interviews it was anticipated that children might be identified as anomalies and as such participants were asked to comment on children's cancer. It was important to establish which types of narratives are entered into explanatory models. Asking participants to recall cases of celebrity cancer would initiate the discussion of the relative importance of narratives. As well as asking about lay epidemiology the study also sought to access participants' reflections on different types of cancer. Clinically and epidemiologically cancer is treated as a multisite and multi-causal disease and the study questioned whether the views of the lay public mirrored the experts in this respect. Despite this need for structural consistency it was equally important that the interview was flexible enough to permit additional salient themes to emerge.

6.2.2.1 The interview

The interviews took place between July 2007 and June 2008. All interviews began with a description of the aims of the study. Rather than introduce lay epidemiology, the stated aim of the study was to gather 'ordinary' views about cancer. The information shared with participants prior to the interview had outlined that the study was part of a PhD project and many participants remembered this. This automatically labelled the researcher as a student. Establishing roles within an interview situation has an impact on the outcome of the process, and the 'student' status of the researcher provided distance from the 'expert' view (Richards and Emslie 2000). Although in this context neither the interviewer nor the interviewee was 'expert', it was not uncommon for participants to state: 'Well, you'll know more than me' and participants often sought clarification from the researcher on specific risks and causes of cancer.

6.2.2.2 Fieldnotes

There is some disagreement about how fieldnotes should be collected and more specifically what information they should include (Emerson et al 2001). Fieldnotes were collated in this study after each interview. These gave general observations about the interview, how it had progressed and impressions on the interviewee. In particular, anything that marked them out. Even from the very early interviews it was apparent that the perceived closeness or 'proximity' to cancer was important and that this was likely to frame participants' overall beliefs. Fieldnotes then became a statement of proximity for each participant and more detailed 'proximity vignettes' appear in Appendix 10.

6.3 Analysis

6.3.1 Design

The utilisation of theory from the outset of the study meant that the big 'themes' were already determined. As such, adopting a framework-type approach (Richie & Spencer 1993) to the analysis may have been useful but ultimately it was decided that the approach may stifle the analysis. Although the themes were pre-determined the analytic process had to be flexible enough to allow other important themes to emerge. If, for example, candidacy had no application in the data, the analyses would have to explore other themes and avenues that might illuminate the content of lay beliefs of cancer.

As the previous chapter on methodological considerations demonstrated, a version of the grounded theory method was adapted. The constant comparative method of looking at transcripts and data was used as an analytic tool. The method allows for the analysis of a single case but at the same time incorporates cross-case analysis. According to Glaser and Strauss (1967) the constant comparative method has four clear stages: comparing incidents applicable to each category, integrating categories, defining the theory and finally writing the theory. Clearly the presence of the 'theory' from the beginning gave the analysis a focus but the analysis did seek to provide a theory about the utility of lay epidemiology. The study was not embarked on with preconceived ideas about the value of lay epidemiology in this context and no hypothesis was tested. From this perspective the analysis was inductive rather than deductive.

6.3.2 Analytic process

The first task in the analytic process is to assign codes to the data that will be built on to create a coding frame. Developing and refining a coding frame is vital because it allows the systematic exploration of data. Individual elements within lay epidemiology provided the starting point for the coding frame. Although beginning the process with fixed codes in mind is not always usual in grounded theory, Kelle (1997) maintained that we are most likely to embark on any analysis with a set of *a priori* codes, which are distinct from the *nvivo* codes that emerge from, and are grounded in, the data.

Each interview was transcribed verbatim and as is customary with good practice in qualitative analysis, each recording was listened to after the interview and again on receipt of the transcript. Initial codes, based on the *a priori* codes from lay epidemiology, were applied to the transcripts. Thereafter new codes were developed and added as patterns and themes emerged. The analysis followed a circular rather than linear process and the coding frame went through a number of iterations. The *a priori* coding frame and the final coding frame appear in Appendix 8. Codes from the initial coding frame were applied to all the transcripts. However, re-reading the transcripts often provided new avenues or possibilities and where appropriate new codes were added. This is consistent with the constant comparative and iterative approach. The data were initially coded manually before the coding frame and transcripts were entered into Nvivo¹². The data were anonymised before being entered into Nvivo. The organisation of nodes and trees gives a helpful ‘filing cabinet’ to store data (See Appendix 9). So, rather than use Nvivo as an analytical prop, it was used merely as a catalogue and reference system. As Mason reminded us:

“Computers cannot perform the creative and intellectual task of devising categories, of deciding which categories or types of data are relevant to the process being investigated or what is a meaningful comparison, or of generating appropriate research questions and propositions with which to interrogate the data.”(Mason 1996:108)

Coding and organising the data is simply the first step to the analysis proper. The data need to be constantly checked and rechecked and eventually stories begin

¹² <http://www.qsrinternational.com>

to take shape. While much is written about coding, this stage in the process is given little attention:

“This is an aspect of analysis that tends not to be described in full, being something that the researcher picks up along the way.” (Barbour 2008:215)

The constant comparative method of reading and re-reading transcripts has been described as ‘a painstaking and somewhat unglamorous process’ (Barbour 2008:217). Yet this meticulous and conscientious exercise is what gives rise to the emergence of the impressions and feelings about the data:

“Ideas occur to us when they please, not when it pleases us... Yet ideas would certainly not come to mind had we not brooded at our desks and searched for answers with passionate devotion.” (Weber 1918)

Interpreting the data generated in interviews was central to this study. Participants provided a series of narratives to evidence their views and the analytic task was judging whether the concepts in lay epidemiology applied to the data.

6.4 Ethical considerations and approval

As shown in section 6.1.2 on the sampling and recruitment process, a number of ethical matters were considered when deciding how study participants might be recruited. Cancer is for many a sensitive area and, as the literature review highlighted, is a topic often attended with fear. This was among the reasons for deciding to ensure that the recruitment did not have a healthcare focus. It was possible that some patients may receive the invitation via their GP practice and misunderstand the aims of the study and become distressed.

The decision to recruit participants from outside the National Health Service resulted in an ethical permission being sought from the University of Glasgow’s Faculty of Medicine Research Ethics Committee. Ethical Approval was granted by the committee in June 2007 (Appendix 1).

Community organisations were contacted once either by letter or email (Appendix 3). No reminders were sent. Posters were placed in local libraries and

community centres. Any additional was initiated by the organisation or the individual volunteer. Involvement was on an entirely voluntary basis. Some organisations invited the researcher to attend a meeting to provide further information. Others contacted the researcher directly. Any community volunteer was provided with an information sheet (Appendix 5), and consented to providing the researcher with contact details. They were given 48 hours to decide if they wanted to take part in the study. The researcher then contacted the volunteer by telephone, again to assess interest and where appropriate arrange a suitable time for interview. Prior to the interview, participants were informed of the purpose of the interview and the consent form was then discussed in full (Appendix 6). It was made clear that they were free to withdraw at any point and could choose not to answer any questions. Interviews were recorded with participants' permission. One participant refused permission for the interview to be recorded. All participant data were kept in accordance with the University of Glasgow's data handling and research governance procedures¹³.

Cancer can be an upsetting area for some and it was anticipated that some of the participants may experience distress during the course of the interviews. Few participants became distressed during the course of the interviews. As an experienced interviewer it was possible to handle these situations empathically.

6.5 Rigour in qualitative research

The ability to adopt a 'smorgasbord' approach in qualitative research has led to questions about its rigour. There remains little agreement on how best to guarantee rigour, though numerous guidelines and checklists provide hints and tips (Hoddinot & Pill 1997; Seale & Silverman 1997; Rogers et al 1998). The lists are not uniform, and contain a range measures thought to add rigour to the process, including: the transparency of the researcher's role or using computer programmes to aid analysis. Collectively, they display a lack of agreement on the 'right way' to approach qualitative research and fail to capture the need for pragmatism in the qualitative research endeavour. Indeed, opting for one over the other introduces the danger of scrabbling for what Barbour (2001) termed,

13 http://www.gla.ac.uk/media/media_46633_en.pdf

the ‘technical fixes’ that have come to represent a proxy for quality. This does not suggest that quality should not be considered, yet some of the techniques like triangulation, respondent validation, and multiple coding, were not applicable in this study (Pope & Mays 2000). This should not detract from the rigorous approach adopted in this study.

6.6 Chapter Summary

This chapter outlined the methodological design and process of the study. The sample was recruited from community organisations and leisure clubs in two communities in Glasgow. One affluent and one deprived. The sample was chosen to reflect ‘ordinary’ views. A total of 31 interviews were conducted. The interviews were loosely structured and a topic guide ensured consistency throughout the interviews. Interview participants were asked to provide details about cases of cancer known to them. The data generated in interviews were analysed by adopting the constant comparative method utilised in grounded theory approaches.

7. Findings

7.1 Findings introduction

Although the interview topic guide and the means of coding those conversations into themes have been discussed in the previous chapter, it is useful to briefly revisit this as it provides an outline for the findings chapter. The primary aim of this study was to consider the utility of the ‘lay epidemiology’ concept when exploring beliefs about cancer. The interviews were informal discussions that centred on the participants’ experience of cancer. A range of themes were introduced in each interview to ensure consistency, though in keeping with qualitative work generally, the interviews were flexible enough to allow participants to introduce subjects important and unique to them

The aim of this chapter is first to introduce the sample in more detail. It focuses on the demographic characteristics of the sample. The findings have then been grouped under three main headings or sections: experience of cancer, meaning and understanding of cancer, and finally, lay epidemiology. Essentially the first theme, experience of cancer provides a routine description of the information imparted during interviews. The second theme, meaning and understanding of cancer, illustrates how this experience has shaped participants’ views of cancer. The final section looks specifically at whether these views and experiences suggest that a lay epidemiological perspective is adopted when thinking about cancer. Both the sections on meaning and understanding and, to a greater extent, the lay epidemiology theme are not descriptions but interpretations of the interview data.

The aim is first to describe the participants’ experience of cancer. Here the focus is on details of individual cases known to the participants as well as to explore different sources of information. Participants have been assigned pseudonyms throughout. What emerged from the experiences shared by participants in the interviews was an insight into the process of developing an explanatory framework of cancer. From close personal experiences and knowledge gleaned from wider, and often removed sources, participants built a personal evidence base. While each is uniquely tailored to the participant’s individual experience, striking similarities are found throughout the spectrum of

understanding. Finally lay epidemiology and its relevance to cancer beliefs will be scrutinised. Held within lay epidemiology are a number of crucial components, including candidacy, anomalous deaths and unwarranted survivals. Each of these will be considered. It is notable that both the chapters on meaning and understanding of cancer and lay epidemiology assume a more discursive tone, and data relevant to the findings of this study is introduced. The final chapter on lay epidemiology in particular consistently contrasts the findings from this study with Davison's.

Although the findings are presented in linear, sequential logic, there is overlap between each section. This is especially true of those sections that consider meaning and understanding and lay epidemiology. Explanations of cause or aetiology for example are found across the chapters.

7.2 Introducing the sample

A total of 31 individuals agreed to participate in the interviews. Most interviews took place in the participants' homes, although five opted to be interviewed at the Section of General Practice and Primary Care, University of Glasgow. One participant chose to be interviewed at her workplace. All interviews were taped with respondents' permission, only one respondent refused permission and on one occasion the recording equipment failed. All audio recordings were transcribed in full.

Two of the interviews were undertaken with married couples, both of whom had agreed to be interviewed but opted to be interviewed at the same time. Other married couples were also interviewed but chose to be interviewed separately. On three occasions another person was present while the interview was being conducted, and although they often contributed or offered opinions they were not regarded as respondents. There is one notable exception to this when one participant's mother offered a particularly pertinent insight into cancer and fatalism and this is noted in Chapter 10 on Lay Epidemiology.

7.2.1 Demographics

Respondents ranged in age from 25 to 83, though the majority were over 50. This marked out the sample in a number of ways. First, most of the sample were retired. More importantly, the age of the respondents provided the opportunity to discuss the changing nature of cancer in light of medical advances. The advantages and disadvantages of this are discussed more fully in Chapter 11, which provides an overall reflection on the study. The majority too were female (22 of 31). More interviews were carried out with those living in the affluent community. All of the participants, with one exception, were or had been married or cohabiting. Four of the participants were widowed or divorced and also lived alone. The remainder lived with their partner or spouse and two respondents lived with other family members. Table 2 outlines respondents' characteristics.

7.3 Sample recruitment

As detailed in the previous chapter a number of community organisations were approached (Appendix 2) in a bid to secure volunteers for the study. The majority of participants were recruited via this method. A series of posters and leaflets were distributed in libraries and community centres in the selected communities (Appendix 4). None of the participants were recruited via this method.

7.4 Experience of cancer

As Table 2 shows the majority of participants were close to someone who had had or was currently experiencing cancer. The majority had experienced cancer among extended family, and this included grandparents and aunts and uncles. Table 2 records the closest experience only. The closest experience was judged to be spouse, followed by parents and then siblings before going on to extended family and wider social networks. Some participants had experience in all categories. Only three respondents reported that they had experienced cancer only amongst their social network.

Table 2 Characteristics of participants

Respondent	Age	Socioeconomic status*	Gender	Employment	Proximity to cancer**
Lisa	45	A	F	Part-time info officer	Spouse
Murray	83	A	M	Retired engineer	Social network
Kathleen	68	A	F	Retired Admin	Extended family
Andrew	57	A	M	Full-time	Extended family
Jessie	63	A	F	Retired nurse	Parent
Elsie	62	A	F	Retired/housewife	Spouse
Jim	64	A	M	Retired police officer	Parent-in-law
Phyllis	58	A	F	Self-employed	Parent
Colin	61	A	M	Management consultant	Extended family
Janet	46	A	F	Nurse	Extended family
Grace	62	A	F	Childcare worker	Spouse
Angus	56	A	M	Self-employed	Sibling
Emily	37	A	F	Optometrist	Parent-in-law
Clare	42	A	F	Self-employed PR	Parents
Jenny	38	A	F	Pharmacist	Social network
Barbara	64	A	F	Retired librarian	Social network
Eileen	72	A	F	Retired Admin	Sibling
Barry	74	A	M	Retired bank manager	Extended family
Betty	61	D	F	Retired	Parent
Charles	74	D	M	Retired Engineer	Spouse
Gary	37	D	M	Unemployed	Parent
Caroline	37	D	F	Carer	Parent-in-law
Karen	25	D	F	Social Care worker	Extended family
Patricia	62	D	F	Retired Community worker	Parents
Pauline	57	D	F	Retired nurse	Extended family
Rose	61	D	F	Long-term sick	Extended family
Josephine	61	D	F	Retired retail	Parent in law
Lorna	57	D	F	Long-term sick	Extended family
Rona	31	D	F	Self-employed PR	Extended family
Peter	67	D	M	Self-employed	Parent in law
Julia	65	D	F	Retired Catering	Parent

7.4.1 Proximity Vignettes

Proximity in this study denotes the participants 'closeness' to cancer. From the earliest interviews it became clear that the level of personal experience of cancer was extremely influential in the participants' beliefs and discussions about cancer. Proximity could be experiential, for example through the cancer event of a spouse but also temporal in terms of how recent the cancer event was. The importance of proximity for the formulation of explanatory models is reiterated throughout the findings chapters. As well as Table 2, which provides a brief outline of proximity, a short vignette of each participant, based on interview fieldnotes, appears in Appendix 10. The detail gives background and context to findings chapters.

8. Experience of cancer

8.1 Introduction

Central to this thesis are the participants' experiences of cancer and these will be described in this chapter. Personal experiences formed the basis of their explanatory models of cancer, which were supplemented with evidence from wider mainstream sources, like the media. Participants' experiences of cancer were wide-ranging. All could provide at least one example of someone they knew with cancer though the level of detail or narrative offered about individual cases varied greatly. Typically participants gave detailed accounts of one or two relatives' or friends' cancers. A handful of respondents felt that cancer had not affected them and could cite no one they regarded as 'close' as having or having had cancer.

As Table 2 in Chapter 7 demonstrated the majority of participants did have what they described as a 'close' experience of cancer. A small number had a spouse with cancer, or a spouse who had died of cancer, a number also had parents or parents-in-law, grandparents, siblings, aunts, uncles and close friends. Ideas about cancer were articulated through these borrowed narratives. Often patient experience is chronicled through the use of narrative and it is usual for research participants to be asked to 'tell their story'. This is the approach used by Health Talk Online¹⁴, the video archive of patient experience in a number of clinical areas, including cancer. The participants in this study show that when asked to talk about cancer, often in abstract terms, even those with little direct experience borrow narratives. This resonates with Kapodi et al's (2005) paper that discussed the importance of availability heuristics. People will discuss the information that they have readily available and they evidence their beliefs by providing anecdotal examples. (Scanlon et al 2006)

8.2 Proximity

Proximity refers to the participant's closeness to cancer. Clearly those with a closer proximity to cancer provided more detailed narratives than those who felt they had not been affected by cancer. Those unaffected talked about cancer in

¹⁴ <http://www.healthtalkonline.org/> accessed 28/10/10

more general terms and merely pooled information from alternative sources, such as the media. Those affected by cancer could often provide very detailed information of cancer journeys and drew comparisons and highlighted differences between the cases they were familiar with. Family dynamics vary significantly. For some participants, the experience of an aunt or uncle was thought to be very close while for others this was barely regarded as being in the family. Those participants with a closer proximity to cancer had deliberated more and had been more questioning about the potential causes of illness in the cases known to them. What emerged was a more reasoned and intricate explanatory model. This group talked about the need for explanations and to understand why the event had or was happening, particularly if no obvious cause was apparent. As Clare demonstrated when discussing her mother's cancer:

So there wasn't any kind of obvious links in that (family) and so I guess that made myself and my sister, who have spent a long time discussing these things, wonder about where it all came from. (Clare 42, Affluent)

Proximity refers not only to relational or kinship closeness but also closeness in time. Those participants with a very recent close experience of cancer tended to offer more and be more thoughtful about the event. For example, Kathleen's friend was undergoing surgery for colorectal cancer on the day of the interview, and she reported seeking out information on her friend's behalf.

8.3 Distant proximity

While those participants with a closer proximity to cancer were more likely to offer information about individual cases in depth, all participants drew on a breadth of information. So, while the intricacies of cases might have been missing from narratives, participants did proffer views and insights into the disease experience of not just family, but friends, and wider social networks. This ranged from neighbours, school-gate peers, fellow club members, churchgoers, and colleagues. Although the sufferer may not have been well-known to the participant they were able to routinely provide detail about their cancer and disease experience. It was clear that in such affiliate organisations or social networks discussions about illness were regular occurrences. The result was akin to 'Chinese whispers' and although the quality of the information may

be dubious, participants accepted these cases as truth or fact. Moreover, many of these half-known cases were critical to views about cancer.

The following extract highlights that information, even from someone quite removed, can impact on the overall cancer belief system. Throughout the interview the participant, Josephine, returned to the unpredictability of cancer, particularly with regard to the speed at which cancer can take hold:

Josephine: What I cannae understands aboot cancer is em the speed, you know how quickly. Now there's a wee boy, I say a wee boy, but I've known him since he was a wee boy em that goes to oor church, he's the minister's son's friend. His mum works round in the chemist and eh I think it's Lymphoma he's got but anyway, and I know there's all different kinds of cancers and all different, but this wee boy has been maybe ongoing for about three years maybe. Noo when he was first diagnosed as I say he got his chemotherapy and his treatment and all the rest of it and he was free of cancer.

I: How old is he?

Josephine: He's twenty-one now. And then, aboot less than a year ago, em, his mum was saying that he was going for tests and he was quite worried but when he came back he was still cancer free. And, it was only a matter of weeks, now when I'm saying a matter of weeks, it was only maybe about three weeks, four weeks, he was back in the hospital, it's all re-appeared and he's back on chemotherapy. And apparently, em, I think he's terminal now because eh, whit dae you call it, the minister was saying a couple a weeks ago when he was, you know, gieing the intimations that the boy had stopped the treatment. (Josephine 61, Deprived)

This extract illustrates two fundamental points. First, cases of cancer that are far removed can be offered as experiential narratives. This is not unique. The interviews are littered with examples of stories from wide social networks. More importantly in the extract above, the most salient factor for Josephine was the 'speed' at which an apparent success story had changed, thus emphasising what she believed to be a major feature of cancer; unpredictability. Being unable to forecast the disease trajectory and outcome are likely to be the root of those universal metaphors that emphasise the irrationality of cancer (Balshem 1991; Lupton 1994).

8.4 The legacy of early memories

Many participants began the interview by telling of their first encounter with, or experience of, cancer. As detailed in the introductory chapter the majority of participants in this study were aged between 55 and 70 and this generation has witnessed dramatic changes in cancer treatment and outcomes. Early experiences were important in formulating their beliefs about cancer. The contrast between past and more recent experiences is touched on in the first extract from Rose, who illustrates the importance of the relationship between experience and understanding. Yet, despite medical advances there is an underlying sense of permanent negativity:

When I was twenty-one, and it came, when I realised what it was, because my aunt had it and I watched her. In they days they didnae have the Macmillan Sisters or they didnae have, you know, the places for them to go. And I watched my mum and her other sister nursing and I saw her degrading, and it lasted a long time. She was ill for a long time. So that was my nearest, that was when I was twenty-one, now that was the first time of actually realising what it was. (Rose 63, Deprived)

My grandfather died of, em cancer, he died in 1962 of cancer rising from a wound or a wart and by the time he died I went to see him in Stobhill then Royal Infirmary for a year before he died and eh it was just awful I mean the whole side of his face it was a wound in his temple and it spread down into his shoulder. And I mean he was like that by the end and I mean it was just awful, you know, I mean it would be awful to see anyone but in someone you loved it was a very, very traumatic experience and I was fourteen or fifteen at the time. Em so I guess that left its mark (Colin 61, Affluent)

8.5 Cancer Narratives

8.5.1 Disease trajectory

Participants provided many detailed examples of cancer among people that they knew. In terms of the general course of the disease, cancer was typically described as either a long, painful process or as an aggressive, fast moving disease that took hold quickly. Neither trajectory was positive, each bringing with it its own difficulty for family and friends. As Grace whose husband died of colorectal cancer, ten years after his initial diagnosis demonstrates:

What I'm scared of is if somebody tells me some relation or other has got cancer I hope they die quickly and didn't go through what Bill had to because he went from fourteen stone to six stone and his watch strap wouldn't fit me. I used to take the links out for him and his wrists were so thin that his watch wouldn't fit me after he died. And I think to myself if they could avoid that, if they can't be cured, if they could avoid that, going through what he went through and the agony and the pain and the indignity of colostomies and things like that, yeah it was, and if they could avoid going through that and sort of go quickly it would be a blessing. (Grace 63, Affluent)

The above description of physical demise is not uncommon, others talked of 'wasting' away or of sufferers being 'shadows of themselves' and cancer had completely 'consumed' them. Yet, the opposite was also true. Some participants were alarmed at the speed of the disease, particularly in what they regarded as largely asymptomatic patients. Angus describes the case of his brother who died of pancreatic cancer:

What I think was, he turned yellow one day he went to the GP and the GP says "Oh you've got jaundice" and then a week later he was yellower and he just wasn't himself. So basically I just said to him "No you're no going back to the GP we'll go down to the Hospital X" and they said "Right we'll keep you in for an examination." Within two days they transferred him to Hospital Y and the usual hospital 'Don't worry it's nothing scary' but then basically, really just within three days he died. (Angus 57, Affluent)

8.5.2 Pre-diagnostic symptoms and delay

This potential for individuals to be apparently healthy and then receive an entirely unexpected cancer diagnosis emphasised the unpredictable nature of the disease. The majority of stories though did involve symptoms, and how the sufferers responded to these symptoms also varied greatly. A number of participants talked about how the patient 'wasn't the type to sit about' and sought help for symptoms promptly. Most sensed that something was wrong. Grace described her husband's symptoms of colorectal cancer as 'all you see on television', yet her husband had not presented to his GP for many months. Although she did not question the potential importance of the delay to diagnosis in her husband's death, Colin did question what might have happened if his brother had presented more promptly:

I mean if he'd gone to the Doctor when he was first aware he was unwell who knows he might have still have been alive today I mean I've got no idea but eh apparently by the time he got into [hospital] he was pretty well eaten away, you know. (Colin 61, Affluent)

Most participants were clear about the importance of early diagnosis. The existence of screening programmes confirmed this. Screening for breast and cervical cancer was widely welcomed but led some to question why screening for other cancer sites was not routinely offered, particularly when it was thought to be relatively straightforward:

Because some people think that everybody should get tested for say, bowel cancer and I think they are going to, well I think women should get tested for ovarian cancer because, that, apparently, is just a blood test (Kathleen 68, Affluent)

The inference then appeared to be that early diagnosis would certainly improve survival and further that the extension of the screening programme would offer undoubted benefits:

The health service could do an awful lot more in terms of screening and as far as I'm concerned that was the intention when it was set up. Prevention is better than cure and a damn site cheaper, better for the patient (Peter 67, Deprived)

Participants regarded speedy treatment as a necessity and policy targets around waiting times drive this. Angus, whose brother had recently been diagnosed with a rare colorectal cancer, illustrates the alarm that can be felt by families of cancer patients:

I think cancer is one of these things where I think we've discovered you have to move very quickly. How quickly is quickly? You know, that's what I don't know how quickly, quickly is? I mean it's taken to get to the stage where Philip [brother] is now about to begin his treatment I would think within the next two to three weeks that's probably been about three months. Now is that quick enough? I don't know. Has that made it harder to treat the cancer? Should we do it as soon as we identify the type. The next day should you be in getting the treatment? I know it couldn't be. the next day because what he said was he's had to have ECG 's and everything because the chemo can kill you as well, but how long should you wait? Cause I feel three months is a long time, you know. (Angus 57, Affluent)

Practitioner delay was also introduced by participants and some general practitioners' reluctance to thoroughly investigate symptoms. Some participants felt that long periods of time elapsed when 'nothing' was done. For some this was not an isolated incident. Julia, whose father had a brain tumour that went undiagnosed for "years", reported that her father had been told that his symptoms were "all in his head". Some years later her sister was treated by her GP for more than 12 months for dyspepsia and was eventually diagnosed with oesophageal cancer. The cancer was 'untreatable' by the time her diagnosis was received. Angus described the case of a colleague who had a 'bad back' and had repeatedly presented to his GP, who had suggested he attend a chiropractor, but received a diagnosis of renal cancer after the delay. Betty talked about the pre-diagnostic phase in her mother's illness, who died of gastric cancer:

My mum, she was for two years going to the toilet, her bowels, going to the toilet all the time and her Doctor kept giving her eh, and I forget the name of the pills now, eh to stop the diarrhoea, and not investigating the cause. (Betty 61, Deprived)

8.5.3 Recurrence

The possibility that cancer could and would most likely recur was frequently discussed. Participants presented a number of cases where cancer had 'come back'. Often the recurrence was speedy and arrived unexpectedly, as Clare described her mother's illness:

Yes, I guess she had (sigh) she was sixty-four when she died I think she would have been sixty when she was diagnosed and she had a mastectomy and chemo and radium. But made a very good recovery and quite a swift recovery and, I suppose I mean with that because also, she was very determined not to let it kind of shut her life down and she had a very clear goal as well, something that she wanted to attend and be part of it, which was an active thing. So that seemed to have focused her hugely and I think to the rest of us it made us sort of think she was going to be okay. But em it did recur (Clare 42, Affluent)

Lisa, whose husband had survived both a primary tumour and a recurrence, talked about how she had once thought that "it always gets you in the end". She told how she had re-evaluated her position in light of her experience and expressed shame at her previous presumptions. Nevertheless, the supposition that recurrence is wholly negative was a commonly held view. Josephine is quite

clear of the benefits of early detection but also that if the cancer returns or develops into 'secondaries', there is little hope:

Aye, I mean I know that you get a tumour or whatever it is you get and I know that there can be secondaries and I mean and I know that em if you catch it before it gets tae the, you know, before it spreads there is a chance. You know but em once the secondaries, you know, once it hits the other organs and you're, you know, that it's curtains, you know what I mean. (Josephine 61, Deprived)

The horror of recurrence was not always borne out in reality. Two participants did provide examples of individuals close to them who had a primary tumour and a recurrence and had survived, one for many years. Here Phyllis describes her mother who, 87:

She's had cancer twice. She had cancer first at sixty-seven, she had breast cancer - smoked from she was thirteen until she was sixty-seven and stopped immediately, of course. She survived that and then when she was eighty-two she had, em, cancer of the uterus, and she had a hysterectomy..... And eh she's still here (Phyllis 58, Affluent)

8.5.4 'Facing the worst' - dealing with cancer

The overall cancer narrative often included comments on the psychological impact that the diagnosis had on the individual concerned. Participants were keen to stress the importance of remaining positive following a diagnosis of cancer, and certainly if not positive then largely uncomplaining. Many participants talked about the manner in which sufferers coped with the disease, particularly emphasising the strength with which it was dealt with. This mirrors much of the literature reviewed in Chapter 3, that looked at cancer metaphors. Hope, resilience and positivity are all common narratives that illustrate the salience of morality in the modern cancer discourse (Lupton 1994; Hawkins 1999; Ehrenrieck 2009). A recurring theme was 'just getting on with it' and 'carrying on' even when sufferers had to 'face the worst'. Kathleen illustrates this with her experience of family members, and in particular a paternal aunt:

Although none of them I suppose, they didn't all react in the same way but I suppose all of them just got on with life. Had the treatment put up with the treatment, and just seemed to get on with their life, you know. The one that died having had the breast cancer first, she was actually invited to stay in the hospital for a longer time

than she did and eh, but she didn't because she had quite a young family and she was the one that definitely just got on with it, you know putting up with having to go on public transport, you know to go for her treatment and then go back and, no matter how bad it was, when it was over having to get on with family life and I think I was aware of that as well. I wasn't that close to her but I was aware of that. (Kathleen 68, Affluent)

Again, this echoes the findings of Blaxter (1982), Cornwell (1984) and Balshem (1991) who show that their respondents were clear that not giving in to disease or lying down to it was critical. While few made a direct link between personality and survival, some had considered it but questioned what this meant for those who did not survive. Throughout her interview Lisa returned to the impact that her husband's diagnosis had had on her overall belief system. This fits with Hunt and Emslie's (2001) assertion that family experience will provide the most influential narratives. Almost all of her cancer beliefs and explanatory model had changed to accommodate a close and obviously traumatic experience:

I: Do you think those kinds of things help with survival then, you know if you do have it?

Lisa: Em, you know, I don't know about that, you would need to ask me that before Alan was ill. Funnily enough, I think I would have said that but maybe because I have heard that so often that I have just accepted it as fact. You know, you hear people say, you know, she's a right, sort of, got a really positive attitude, you know she'll fight this kind of thing, as if people who actually die of cancer are weaker and less resolute than other people (Lisa 45, Affluent)

By noting that her presumptions might suggest that "people who actually die of cancer are weaker and less resolute", echoes the stories shared in Hawkin's pathographies, where the weakness of those who succumb to cancer is inferred (Hawkins 1999). So while positive attitude has been championed and thought to help with survival, there were also those that were thought to have 'given up'. Gary reflects on the case of his cousin, who had died in her 40s, and made a more obvious link between attitude and survival:

She was eh in her forties and left a young family, a wee boy thirteen, I say young the daughter was twenty-one and the boy was fourteen it was really sad, you know. But she, there was other things involved there, but she seemed to gie up, you know, too easy, you know, you hear people fighting it and no wanting tae die but she gied up I don't

know what happened I think just an abusive relationship there, you know. But, you know, how people get, after the fact, they make wee comments and all that but that seemed to be the general picture. (Gary 37, Deprived)

Both Gary and Lisa use the word fight. The pervasiveness of military metaphors in relation to cancer is well-established (Sontag 1978, Seale 2001a). The idea that cancer was something to be fought, a battle entered into, was raised again and again. Even when facing a terminal diagnosis respondents were clear that the proper course of action was ‘not to let it beat you’ as Jessie, who volunteered in a hospice stressed:

Well if you go into that atmosphere and found how these people have accepted their illness with great fortitude. They are very brave they have their sad moments, don’t get me wrong, its not all just fun and games but there’s very little doom and gloom, they seem to have accepted, they’ve got their diagnosis and its right lets get on with life, what we’ve got left (Jessie 68, Affluent)

Yet, Jessie was so clear of the negative impact of a cancer diagnosis that she removed the mirrors from her house while she was caring for her mother, in order that her mother would not witness her demise. Some participants decided to withhold information about diagnoses, especially to elderly relatives. Betty told that her mother-in-law was terrified of cancer and asked that professionals did not disclose her diagnosis.

Sontag (1978) first raised the notion that the stigma associated with cancer was as bad as the disease itself. While the depth of the stigma has been questioned, some of the participants, particularly those in the older generation allude to the continued fear of the most dreaded disease, in spite of the advances:

We’re all still scared of it but then it wasn’t spoken about the same as it’s spoken about now. (Rose 61 Deprived)

Balanced against the fear though was the idea that advances have been made and most participants were able to share success stories.

8.6 Success stories

While most of the narratives were about cancer deaths, there were some positive experiences. Some participants presented examples of sufferers who had defied medical opinion. Colin talked of a friend, who, when diagnosed with leukaemia in 1986, was given a '50/50 chance' but is now 'as fit as a fiddle'. Similarly Emily told of her father-in-law, who had also been disease free for many years, despite an initially bleak prognosis. Phyllis' mother, had overcome cancer twice. More generally, there was widespread acceptance that, although they may not know many success stories personally, improvements in survival and treatment were could not be denied:

I think that's the instantaneous thing because I know a lot more people who have died from cancer than have recovered from it. So while I automatically think, 'Oh that's terminal' I actually know that it's not, em because I have family members that have had cancer and are now fine (Rona 31, Deprived)

Clare demonstrates that she sees beyond her immediate experience of losing both her parents and a close friend to cancer:

I say that (cancer equals death) because that's how it is for me, that's the first thing that comes into my head because that's what my very direct experience of it, has resulted in that. So I feel that but I know if people ask me, do I think everyone dies of cancer? No I don't think that at all. Em, the things that I tend to read and become aware of is the fact that more and more people live with it and survive it and get over it and don't even really experience it and I suppose em been more aware of that, you know. I couldn't, I'm trying to remember any of the statistics but I know I have read about different things, about things actually, you know, rates of recovery improving and better systems of treatment and all of that kind of thing. And less invasive techniques as well when they're actually operating. So yes my immediate view is quite negative but my wider view isn't. (Clare 42, Affluent)

8.7 Lay or expert accounts?

Much has been said about the expert patient (Department of Health 2001; Shaw 2002). Armstrong and Murphy (2008) describe the 'weaving' of lay and expert information in patient narratives. Undoubtedly those with a close experience of cancer had been privy to information about their loved one's case and as such discussed cases with more of an expert tone. Terminology about treatment was

a central part of many narratives. Angus relates information from a consultant and describes the ‘revolutionary’ treatment planned for his brother:

He (consultant) said the way forward was CHOP-R, which is, you’ve probably never heard of CHOP-R either. It’s some kind of chemotherapy with an additional chemical in it. And he says really if you use this it will kill everything in your body, it will kill it, it will also destroy your bone marrow so you will need a bone marrow transplant. One of the strange things the oncologists who he’s attending they said “We’ll use chemo, we’ll extract some of your bone marrow which is infected and then we’ll re-inject it into you after the treatment.” And he said “But it’s infected your re-injecting infection” and the Professor in London said “Yeah, have you any brothers?” and he said “Yeah” and he said “Well get some of theirs if they’re compatible get some of theirs and get that back into you. Very risky because your antibodies may go for it but it’s the best way.” (Angus, 57 Affluent)

Although Angus’ example is a complex one, participants did speak a common cancer language that featured in most accounts. The expert stretches beyond the patient and extends to ‘lay’ audiences. Participants were aware of the chemotherapy, radiotherapy and the side-effects of some treatments, the most obvious being hair loss, remission and secondaries. The key stages of the cancer journey were well understood and medical jargon was employed easily throughout.

8.8 Sources and quality of information

By foregrounding stories of close family and friends, the participants demonstrated that personal experience contributes the bulk of knowledge to cancer belief systems. Yet personal experience is by no means the sole source of knowledge and information about cancer.

There was a tendency for participants to mention information received without citing the source. Sentences often began with ‘They say....’ without ever detailing who ‘they’ actually are. This was also found by Calnan (1987) who reported that in his study women from social classes I and II were more likely to use such terms, which he interpreted as seeking credence for their accounts. For participants in this study it was sometimes clear, when they were talking about individual cases that they were referring to medical professionals. Generally ‘they’ was used to describe the wider research community and the media:

Well they say that mobile phones give you cancer (Rona 31 Deprived)

Your lifestyle sometimes they say now, you know, obesity eh staying too near pylons (Gary 37 Deprived)

Well they say it's diet as well, it's doon tae diet, you know (Josephine 61 Deprived)

More often participants cited their information source. The media, in all its forms, was a widespread source of knowledge. Participants typically talked about newspaper articles, television documentaries and the Internet and gleaned information from all such sources:

I read as well, I tend to kind of read medical articles and things like that and I watch documentaries, you know I went into a site, because actually one of my friends in fact she was at the meeting has had an operation for bowel cancer, I did go into a site, the bowel cancer site for the first time. (Kathleen, 68 Affluent)

Some participants talked about the sheer volume of, often conflicting, information. While many recognised the need to inform people, some expressed the feeling that messages should be treated with caution. Concentrating on the fearful aspects of cancer is common in the media and the suggestion of ever-more risk factors leads to the supposition that “everything causes cancer” (Clarke & Everest 2006; Niederdeppe & Levy 2007). There is a danger that messages can become counter-productive:

I think it's sometimes the little things that are so ludicrous that you think sometimes people feel bombarded with so many things that you should be doing, shouldn't be doing. What's next? Oh don't bother, this is as good as whatever and I think people get sick of the whole thing and I think oh whatever I'll just do what suits me (Emily 37, Affluent)

Or potentially harmful:

I think there's too many mixed messages for people because I think some people and I've got friends that do this. They look up things on the internet and they imagine they're dying and they've got this and they've got that and I just think that sometimes too much

information for some can be a bad thing because they then take it literally and if they then know what symptoms are or what to look for and I don't think they need to know because some people make them apply to themselves so if you're getting mixed information then they are doing one thing but on the other hand they're be doing it and they apply that literally to their life and then 6 months later they hear that that's wrong and they are sent into a frenzy and a panic and they think that they've maybe done themselves damage you know about doing it you know. I think anybody can write reports on things and publish, can't they? They can say whatever they want and I think things should be taken with an element of caution. (Rona 31 Deprived)

8.9 Celebrity

Although the media report breakthroughs in cancer treatment and trail cures, and also engage in public health activity by highlighting risk factors, the majority of information centres around celebrities with cancer. Participants were asked in interviews to think about celebrities with cancer. According to lay epidemiology data is gathered from an array of sources and it was important to ascertain if celebrity experience filtered into explanatory models. Often however participants raised celebrity cases unprompted. Celebrity stories are used as evidence in the same way as family and friends. Their stories can have an obvious and lasting impression. As Chapter 9 details, Roy Castle has become synonymous with passive smoking.

Although many celebrities were mentioned during the interviews, Kylie Minogue was introduced most frequently. Although the interviews took place some two years after Kylie's diagnosis, it did receive a great deal of media attention. So much so that the impact was felt by health services (Chapman et al 2005). A celebrity cancer case can remain in the public eye for many months and effectively follow patients throughout their journey. Coverage of Jade Goody's cervical cancer was analysed in a recent paper by Hilton and Hunt (2010). They show that although there were obvious increases in coverage according to changes in her status, for example there were more stories around the time that cancer 'had spread', stories continued across the time from diagnosis until her death in March 2009. It is not surprising then that Kylie's Minogue's cancer appeared fresh in participants' minds. Although anomalous cases will be discussed in more detail in Chapter 10, for some of the younger female

participants especially, Kylie Minogue's diagnosis did not fit with typical explanatory model because she represented the typical embodiment of health:

God, I can't believe it because she does kind of present a kind of healthy looking em image, which not all celebrities do. I mean quite a few of them, although they might be slim and attractive, you feel that a lot of it is, well they may be cosmetically enhanced or they may have drug problems so their health, you know they, might not be looking after their bodies and I could be totally wrong about this because I don't know a great deal about Kylie Minogue but she always looked to me as a very healthy person, you know her skin and her teeth and her eyes and she looks as if she eats very healthily, she looks like she looks after herself, and obviously exercises, I think I would have been quite shocked if it hadn't been for my husband's experience, yeah (Lisa 45, Affluent)

Again I put that down to bad luck rather than anything else cause obviously she's, well she looks like a healthy, she doesn't look the type of person that's going to get cancer but then I am aware that breast cancer can occur in younger women cause you read magazine about people in their twenties etc. (Emily 37, Affluent)

There was acknowledgement though that Kylie represented a success story:

But noo you hear of people getting cancer and beating it and you hear them on the telly noo like maistly mainly celebrities and stuff like that getting cancer and you hear of them. I think is it Kylie Minogue she's one of the ones that just recently beat it, you know, so it makes you mair aware that it can be treated and people can beat it, you know. (Caroline 37, Deprived)

Caroline's repeated use of the word 'beat' raises the issue of cancer metaphors. Clive Seale (2001a, 2001b) concluded that sporting stories were as common as military metaphors when reporting individual cancer cases and often the two were combined. Kathleen introduced Jane Tomlinson and her 'attitude' when discussing how people deal with a cancer diagnosis:

Oh look at that woman, Jane Tomlinson, her 10 year old son just got presented with her CBE all the years she survived after she was diagnosed and I mean most people wouldn't attempt, whether they had cancer or not would have attempted to do the sports things that she did for fundraising, these triathlons and things like that but she was still only in her early 40s but I think she was diagnosed at 28 or something like that and I don't think she would have had anything like the life she had if she hadn't had the attitude (Kathleen 68, Affluent)

Barry though had quite a different view of Jane Tomlinson:

She made herself famous because she had it (Barry, 74 Affluent)

Celebrity stories also introduced participants to information that they may not readily have had via their families. This strengthens Sanders et al's (2003) assertion that people draw on only what is available to them when explaining their health belief models. In the following extract Betty demonstrates that she cannot provide a reason why 'men' get cancer :

Eh well I don't know how men get cancer eh likes of Bob Champion the jockey eh I don't know how he got cancer, you know, in the testicles I don't know is it chemicals that build up in the body, I don't know. (Betty 61, Deprived)

Celebrity was discussed in relation to cancer to evidence that 'everyon' can get cancer and no one is immune. In particular that money is of no consequence, as Kathleen states:

Well, money doesn't matter does it? I mean King George VI, he died of cancer didn't he, lung I think (Kathleen 68, Affluent)

8.10 Differences in accounts of experience

8.10.1 Age

The majority of respondents in this study were over 55. They had seen remarkable changes in the social understanding of cancer. The transition from the 'Big C' to a more positive outlook was raised in many of the interviews. Given that age is a significant risk factor for cancer it is surprising that Murray, the oldest respondent, had so little direct experience or proximity via family and friends. Similarly, Karen, the youngest respondent had limited direct experience.

8.10.2 Gender

Conventionally, health is thought to be the preserve of women. They are often presumed to be the keepers of family health information (Graham 1984). In this study women were more likely to have been carers for cancer sufferers and a number described nursing parents or spouses. Though there were a handful of

male participants who had adopted an interest in cancer because of a close family cancer experience, the women in study gave more. A number of couples were interviewed, some together and others separately. Often, men looked to their spouses for more detail and confirmation. Typically women appeared to have greater general awareness and more complex explanatory models of cancer.

8.10.3 Affluence and deprivation

Those in more deprived communities are more likely to experience cancer and have poorer outcomes following diagnosis (Brewster et al 2001). This was not reflected in this study. While those in both communities had a wide range of experience of cancer those in affluent communities were more likely to have either a spouse or a sibling with cancer than those in the deprived community. There was also a tendency for those in affluent communities to describe closer relationships within families. Among the participants in the affluent community were a number of professional women in their 30s and 40s and this group tended to be most aware. They had all shared a close experience of cancer and as a group they were most articulate. Such a demographic group was not represented in the deprived community. If comparisons are drawn between older women in either community, those in the affluent community did not portray greater awareness. Similar men in both communities, with little experience of cancer had similar levels of awareness. An additional difference between the communities was that those in the deprived community were more likely to offer ‘triggers’ as an explanation for cancer.

Participants were aware that the study was being conducted across the two communities. This prompted some, particularly in the deprived community, to comment on the health differences between the two communities.

8.10.3.1 The health divide: health determinants

There was some disagreement at the extent to which cancer was socially patterned:

“ it (cancer) just seems to have a certain predictability for people who are living in disadvantaged areas.” (Clare 42, Affluent)

“Um, I don’t know if poverty, social deprivation have a role to play ... I ruled those out yes because it seems, as far as I can gather cancer can strike right across the social spectrum and across income scales” (Murray 83, Affluent)

Those in the affluent community attributed the health differences between the communities to behavioural differences. Those living in deprived communities had poorer health outcomes because they engaged in risky behaviours, in spite of being aware of the dangers. Lisa, initially at least, focuses firmly on behaviour but shies away from apportioning blame:

“ I think, you know, people really, you know with that sort of, you know the lower socio-economic group who are really obese and smoking heavily and you know their lifestyle is quite likely to shorten their life dramatically. I think the message has pretty much filtered down, I think people pretty much know what they need to do but that’s not to blame these people either because, you know, to be honest I think if I lived in deprived community x and didn’t have a job and no money and was living on benefits you know had no real life chances or opportunity to better my lot, I don’t really know that I would alter my lifestyle I think people here (affluent community) take a long-term view. You know, its just a stone cold fact that people here are, the vast majority of them are gonna live, you know, to a ripe old age and people in deprived community are not. They just don’t have the same life chances, so I think you can’t impose the same requirements on people, I’m very much a believer in that. (Lisa 45 Affluent)

Well you keep reading about the different age that people will live to in the leafy suburbs of Bearsden & Milngavie, as opposed to over in the East End or something like that, so I think maybe, statistically a lot more people still smoke, I think unfortunately a lot of people who don’t have money smoke and its a shame because its such a waste of money but on the other hand once you’re hooked on smoking and that’s maybe the only pleasure you’ve got, you will try and find the money for cigarettes (Kathleen, 68 Affluent)

Andrew sums up the differences and refers to directly to culture, and introduces the idea of fatalism:

Well, the life expectancy in Shettleston is I think about 56 I think there’s a massive cultural education change needed. I mean it was nothing to me to fall out of a car drunk driving in the 70s, they should be doing that with drugs ... I don’t think drugs is as big a problem as they make out. They pick on easy things to improve; I think they need to improve people’s optimism, which is a hard thing to do Better education from 5 years and up and they could do

what they have done with smoking. Not even smoking, I can't understand why girls are smoking more. One of my daughters said to me. I was picking her up from school and I was smoking up until 1990, and she said to me 'Gonna no smoke, I don't like my friends seeing you smoking', now that's good education, but that's happening in Bearsden, I don't know if its happening in the east end? The thing about the east end, just while we are talking here, there's a fatalism about the east end you know, 'I won't get anywhere', they will not rise above their station and they have terrible fatalism about life.....

Later, he then goes on to consider the temporal shifts in experience:

Andrew: Well, I wonder, if a 20 year old from the east end, you know ... if you said to me in 1970, you know if someone said to me 'He's got cancer', didn't matter what type it was, you'd think he's not long for this world and maybe, if you say to someone in Shettleston now, a 20 year old, they'd say the same

I: Because?

Andrew: Because Shettleston now is not unlike ... well, Anderston 20 years ago, uh huh.

Andrew's idea that there is effectively a trickle down effect from affluent to deprived communities with respect to health promotion messages is interesting. It ties in with Lawlor et al's (2003) work that considered the relationship between lay epidemiology, the prevention paradox and smoking cessation. The variation in the experience of health in affluent and deprived communities is captured by epidemiological data. That aspects of health promotion may be received differently in different communities is not so widely accepted.

Those living in the deprived communities were equally wedded to the idea that behavioural differences could explain the varied health experience. Gary was unemployed at the time of interview and could personally relate to some of the problems faced by those in the east end. Gary, summarises the multifarious problems associated with multiple deprivation:

See I believe, see the noo, eh we're probably the poorest financially noo we've ever been, you know. Just because of finishing University and no a full time wage coming in for five years. See the stress wae that, that goes along wae that like, really. It's the first time I would say, I still widnae say we were living in poverty right we're no rich by any manner of means but see the likes of Joe and Ryan and Ellie, they don't go without a lot of things, they go without a summer

holiday we maybe go to the caravans, you know but we don't go a foreign holiday. See the stress, no having tae worry about things like, certain things like I think that could be a big, big factor and they say the sun has got qualities like, we were talking about sun giving you cancer but the sun is also good for your skin, you know. And you probably find people go two, three different holidays a year ... and they've probably got a lot mair room as well, you know, space wise in the hoose and eh they've probably got a better social life. Money gies you, we all know money disnae buy happiness, but it gies you a lot of different options, you know. And like going back tae the food - people in the East End of Glasgow buy what they can afford. Whereas people on that side of the city could buy anything they want, you know, no anything they want, but you now what I mean they're no restricted tae We'd like tae buy fresh fruit every day, well if I had money I would buy it every day. And you've been up and doon Shettleston Road there's one, two, three, four, five, six, seven, there's about ten pubs in less than a mile, you know, so a lot of people in the east end their alcohol consumption is probably a wee bit mair. Whereas if they had a wee bit mair money instead of having a spare fifteen quid going to the pub if they had a spare couple of hundred quid they'd maybe dae other things. So I think that's a big factor. you know, lifestyle's definitely, there must be something in that, you know, well it's kind of telling us isn't it if you're living ten, twelve years more. (Gary 37, Deprived)

Gary, perhaps because of his own situation tended to be more understanding of the lack of choice faced by those living in the east end. Rona talked about the importance of awareness:

I think a lot of that is education, I think a lot of that is lifestyle people, a lot of people thing that this is o.k. because I'll not get it anyway, they tend to, and I live in the east end, and I'm born and bred in the east end but people do tend to drink more, people do tend to smoke more and there's people in the west end or Bearsden will take their children to museums, will take their kids to restaurants, whereas in the east end they get fried food and they get stuck in front of a computer game. Whereas if you even drive to Kelvingrove, you will see kids playing football in the garden, running about, having fun, it doesn't even cost anything and its free but people in the east end tend to put more of an emphasis, if you've got money, then you go and drink at the weekend and new outfits and the kids have the best computer games and for them that makes their lives richer, its priorities for whatever reason. A lot of it is how they are brought up as well and things are passed down as well. They see parents, you know its all right for them, but they hardly leave the east end so they don't know that this other world exists two miles form their doorstep. Its ignorance a lot of it I think, but a lot of it is not necessarily bad ignorance, its just unfortunate (Rona 31, Deprived)

Priorities were also touched on by Josephine:

Josephine: What I mean, so this is what I'm saying, when you're saying about em the poor health and all the rest of it I think a lot of it comes doon an all tae peoples ain perceptions eh whit's their priorities, you know, I mean eh...

I: So, do you think health isn't a priority?

Josephine: I would think that would be your number one priority but as I say they've got their drink and their drugs and, you know, all this before they think of food, you know what I mean? And Tollcross, the east end has got a high percentage of drug use so everything else is all further doon the list of priorities, you know, like their heating and, you know, their food and their whatever. (Josephine 61 Deprived)

The extracts from Roan and Josephine represent a departure from the findings in Blaxter (1982) and Cornwell's (1984) work, where respondents were reluctant to apportion blame for ill-health on individuals. Indeed, while Lisa understands that those in deprived communities simply make the 'wrong' choice, she continues to place the onus of the individual rather than society.

While most recognised the health differences between the communities, Charles questioned the validity of the statistics:

Im just wondering where they get their statistics from honest to God, if you've never worked in your life, if your mother and father have never worked so your on that pool of not working, eat fruit nah don't bother with fruit, cigarettes, tonic wine, if you abuse your body its inevitable your not going to live long but to say that all the people up to Shettleston. We know a lot of, you want to try some of the housing associations go out and see some of the old folks homes see some of the old people that are in there in the east end of Glasgow, its just the same as anywhere else I should imagine. (Charles 74 Deprived)

Participants in both communities recognise that behaviour is socially patterned. Some, like Gary, see structural difficulties and barriers impeding the adoption of a healthy lifestyle in deprived communities. Most participants however saw the health and behavioural differences as the result of poor choices. All showed that the responsibility for health lies with the individual.

8.11 Chapter Summary

This chapter has outlined the participants' experience of cancer. The findings show that although those with a close experience of cancer provide more detailed information of individual cases, those with less direct experience also share stories, or borrowed narratives, that have aided the development of a cancer belief system. Commentators from Sontag (1978) to Clarke and Everest (2006) have depicted the fear associated with cancer and shown that this negative tag is tenacious. Although vast improvements have been made and participants recognise this advance, the uncertainty remains. Comaroff and Macguire (1982) suggest the existence of uncertainty in the context of hope can prove a difficult area to reconcile. Experiences, while individual were also universal and participants described a handful of common disease scenarios. Proximity to cancer is vital for in shaping views and beliefs and the paucity of opinions in those without close proximity is akin to Herzlich's (1973) notion that the reserve of health is called on, only when a problem arises. Demographic characteristics are of little consequence in this context, though women typically offered more sophisticated and thoughtful explanatory models. The following chapter will return to some of these issues and focus on the meaning and understanding of cancer that participants have derived from their experience.

9. Meaning and Understanding of Cancer

9.1 Introduction

The previous chapter demonstrated that respondents drew on an array of different types of data when formulating their beliefs about cancer. Beliefs are articulated through a series of narratives, which are used as evidence (Scanlon 2006). Though close proximity to cancer is important, stories were rarely confined to immediate personal experience and also include borrowed narratives. These are also interspersed with information from mainstream health education and the mass media. What emerges is a sophisticated and dynamic schema. It is this experiential schema that aids their understanding of cancer and it is from these stories that they have derived meaning. Though the schema is individual to them, the addition of mainstream information means that similarities can be found across narratives. This chapter will tackle the meaning and understanding of cancer among participants. It will focus on key areas: what cancer means and respondents understanding of why cancer happens.

9.2 Meaning?

Cancer meant many things. Respondents immediately mentioned research, science, illness, treatment, medical advance and death. The general tenor was negative. Fear was paramount and cancer had connotations of unpleasant treatment, uncertainty and, for some respondents in this study, the death of a loved one. Cancer is synonymous with fear and this reaction from participants here is well-documented elsewhere (Sontag 1978, Balshem 1991, Lupton 1994, Scanlon et al 2006). Despite such negativity, most respondents articulated with clarity that much had changed in the landscape of cancer. There was recognition that advances made in survival and treatments necessitated a reworking of the meaning of cancer in the last 30 years.

9.2.1 Changes in meaning: the move away from the Big C

As has been noted in previous chapters, the majority of respondents in this study were over 55, which allowed for reflection on changing trends. It was apparent

that, at least in theory, cancer now held a different meaning. Many discussed the stigma that once surrounded cancer and the general reluctance to talk about the disease (Sontag 1978, Paterson 1987). The 'Big C' dominated the cancer discourse in their formative years. Often the word was 'whispered'. It was not uncommon for participants to admit that they had not been aware until many years later that a relative or neighbour had died of cancer. Other studies have similarly found shame and secrecy associated with cancer, particularly amongst older interviewees (Scanlon et al 2006). The source of such stigma was thought to be ignorance, particularly around causality. This was especially pertinent in a time when most major disease was infectious. Moreover, cancer meant death and death brought its own taboo. The following extracts symbolise the former status of cancer:

I mean to me it's a sort of biblical, mythical thing, the Big C ooh, and I'm sure that prevailed through ignorance and I'm sure from the medical profession as well. 'Oh well ill just shut the door on that, the Big C.' (Charles 74 Deprived)

See, when I was in my twenties if you had say Mrs Brown in the next close had cancer it was whispered and within what, maybe not even as long as a year, the poor woman would be dead, you know, that's how... She had cancer - that was the end. (Elsie 63 Affluent)

When I was in my teens the 'Big C' you didn't talk about it, if somebody got cancer- mind you didn't hear of that many people because they didn't talk about it. But eh I mean people died of stomach-ache whereas it was probably cancer that they had but you never heard about it. (Angus 56, Affluent)

Because it was fatal in a very short time, or it was thought to be fatal in a very short time and there was something taboo about it for some reason. (Barry, 74 Affluent)

Well-documented medical advances, less of a taboo surrounding death and the relative freedom with which cancer is discussed have all resulted in a shift in meaning. So while the meaning embodied in the 'the Big C' was clearly powerful, some participants reported that they now thought about cancer in terms of serious illness rather than certain death. Kathleen comments on this change:

My initial reaction is not what it might have been say 20 years ago because I know that so much more can be done, survival rates are

better and I've actually got quite a lot of experience through various friends and things like that that have you who have had cancer and are still with us. So, I obviously think yes, it's a worrying thing to have but I don't think it's the death sentence it used to be (Kathleen 68, Affluent)

It was not simply time that had challenged preconceptions about cancer, experience too could force a re-evaluation. Nearly all participants knew someone that had survived or was currently living with cancer. Lisa's husband had recently survived cancer and she spoke frequently of her recent change in attitude:

I: Had you always thought about cancer in terms of dying?

Lisa: Oh yes, uh huh, definitely. Yeah, I did, in fact I've said to people in the past, I've had discussions with people which I'm now quite ashamed of, to the effects of, 'Well, it always gets you in the end' You know maybe people appear to have recovered you know? Because I've known some women of my own age, you know when I was younger, in their 30s, you know early 30s and had made a good recovery and everyone was like, 'oh that's great, oh her hair's grown back, everything's ok' and then got a secondary and died. So, yeah, my definite perception was that um, it'll get you sooner or later (Lisa 47, Affluent)

This reflection from Lisa illustrates an inherent contradiction in many of the interviews. A shift in attitude towards cancer has taken place and many would like to trust improvements but, instinctively, cancer remains frightening territory. The uncertainty, even accounting for improvements in survival, is pervasive (Commaroff & Maguire 1982). Among these participants, there is a need to be hopeful, not only because people close to them have cancer but also for their own futures. Hope has become a major cancer narrative (Lupton 1994; Ehrenreich 2009).

9.2.2 Cancer as tragedy

The idea that cancer meant tragedy was often referred to throughout the interviews. Janet recounts the impact of cancer:

Yeah, Sally died of oral cancer. She had two wobbly teeth at the front and within a year she was dead. And that was really difficult it was horrible actually because, you know, she came to our wedding and that's the last time I ever saw her and my uncle committed suicide

cause he couldn't live without her cause it had all happened so fast. That was very tragic and em I was very close to her. (Janet 46 Affluent)

Lives cut unexpectedly short were frequently described. Caroline talked about a school-friend, who died of leukaemia when she was a teenager:

Well she was a perfectly healthy young lassie until that it was a shock. aye. The only time that her Ma had said was a difference was she died on the 7th July and it was the summer and the only thing that she noticed was that she'd commented on several times was bruising, she was bruising very easily. But she thought that was her just oot playing wae her shorts oan but that's what they said that she was bruising very easy. (Caroline 37 Deprived)

Age is an important caveat. There was a tendency for participants to see cancer in older adults, not as a tragedy but an acceptance that 'you've got to die of something':

And although it was a terrible death for my mother, her actual death bed was excruciating to witness but my mother-in-law just slipped away, so I accepted that you've got to die with something, you know, that I would rather it had been that way than an accident (Betty 61 Deprived)

9.2.3 Cancer is unpredictable

Experience of cancer often led participants to believe that cancer was largely unpredictable. This unpredictability manifested itself in many ways. Sudden onset of cancer or symptoms led Angus to claim

You never know when you've got it. I could have it just now and I don't know, there are no signs until it's usually almost too late. (Angus 54, Affluent)

Angus' views have been found in other studies, and to believe that cancer assumes a silent quality is common (Balschem 1991; Scanlon 2006). The unknown nature of cancer was confirmed by many examples of events in seemingly healthy and asymptomatic individuals or a diagnosis in an individual with apparently benign symptoms. Karen provided an example of a 19-year-old school friend who had a 'sore leg' and died a short time later:

Just a pain in her leg she was having for a couple of months and went back to the Doctors, back and forth to the Doctors and I actually remember cause I met her in the Doctors one day, my friend had a wee girl, and we were taking her in to see the Health Midwife, no the Midwife the Health Visitor, and she was there again wae a sore leg. And a few weeks later she was dead, so that was cancer. (Karen 25 Deprived)

The unpredictable disease experience was discussed by some participants in the context of those who were now thought to be ‘clear of cancer’ or in remission, but the disease recurred and spread very quickly. Cancer was thought also to ‘hit’ unpredictably. Participants offered many stories of cancer sufferers who did not fit the expected cancer profile, so for example, lung cancer sufferers who had never smoked. Equally, some had experienced cases where cancer was believed to be terminal, yet the sufferer had survived until many years later. These anecdotes emphasised the inability even of science to predict outcomes. The following extract captures the unpredictable nature of cancer:

It’s a completely (sigh) random strange disease that affects people totally differently. Some people can fight it for ages, some people it crashes incredibly quickly and I don’t know how you make sense of that. (Clare 42, Affluent)

9.3 Cancer: one disease or many?

Cancer was first introduced in the interviews in general terms and this generality was reflected in responses. When providing individual narratives the focus tended to be on cancer, rather than a site-specific disease and often such information was only introduced on prompting. There were exceptions. For example, Lisa always referred to her mother-in-law’s illness as “non-smoking related lung cancer”. Clare, who had lost both parents to cancer emphasised that these were different cancers, and this she believed was significant in terms of her own risk. Similarly, when reflecting on cause, cancer was often referred to collectively. Rarely was risk specified in relation to site when talking about environmental hazards, for example. Yet, more obvious links were made between smoking and lung cancer and sun exposure and skin cancer. Perceived protective behaviours, like drinking green tea, or eating broccoli, applied generally. This should not imply that an understanding of the site-specific nature of cancer was lacking because all participants gave examples of what one respondent called ‘varieties’ of cancer. It was not always clear if participants

thought about cancer as one disease that simply targeted many different areas of the body or if they saw cancer as an umbrella term for a host of diseases. There is some evidence to suggest the former:

I think probably cancer is a kind of term that covers, but its usually something, I'm not medical, within the cells or something like that so I suppose it possibly is fair to just have one covering term, I tend to probably think of it as one disease striking in different places. (Eileen 72, Affluent)

Elsie though displayed some understanding of cancer assuming different properties depending on site:

When you say cancer I think of a big lumpy tumour. Em, which shouldn't be there eh and generally, well not generally, sometimes they're inside the body, sometimes they come out of the body. So if they do come out in lumps then people notice them and can go and get them attended to. And further Me, oh dear I don't know, well I presume for example, like leukaemia that type of thing, I think that's different, that's not, to me blood is flowing through the body while in tissue it's stationary and it's the cells that develop from it. (Elsie 63, Affluent)

Accounts of both common and rare forms of cancer were shared. Breast cancer was the most frequent and nearly all the participants could provide at least one example of someone with breast cancer. Breast cancer was also referred to in relation to screening, prophylactic mastectomies and heredity. Colorectal cancers too were common, though the commonest cancer, lung cancer was cited less frequently. The frequent appearance of breast cancer may reflect the relatively high profile of breast cancer (Gottlieb 2001). Lisa talked about the media's treatment of breast cancer:

There is more media coverage given to breast cancer, I would say now, maybe in retrospect, it gets too high a profile. Not that it shouldn't, but I think that sometimes male cancers aren't seen in the same, they are not as sexy and not dealt with in the same way, but I suppose when I think about it, and this has only just occurred to me now, I possibly thought of cancer as being something that affected women more than men which is probably nonsense (Lisa 45, Affluent)

Lisa's reflection, not only on the attention given breast cancer but on her previous assumption that cancer affects women is important. It suggests that she

had previously relied on societal level data to populate her explanatory model. Her very recent experience with her husband's cancer demonstrates that one 'new' case can entirely change her viewpoint.

9.4 Cancer is common

Participants generally felt that cancer was common and was becoming more so. The well-documented change in attitude towards openness in cancer might suggest that cancer is not more common, but more public. Nevertheless, participants did not see this as an artefact, they believed that there was a higher incidence. The population risk of one in three was recognised by many, though this level surprised some. Yet, many felt that they heard about cancer 'more and more'. Josephine stated that she felt that people were 'catching cancer like the cold'. This is echoed by Karen:

"I feel as if cancer's out there and it's not budging and it's just as you kind of go along if there's not one person got it you hear of somebody else having it or if you could hear a conversation amongst other people whose talking about somebody whose got cancer, there's quite a lot, a lot of people. (Karen 25, Deprived)"

Lisa described cancer as an epidemic but, as the following extract shows, when she considered cancer in the context of an overall increase in life expectancy, she shifts her position before returning to her original point:

I mean, both before and after Alan was diagnosed, I do know so many people who have had it. Their parents have died of it and it seemed to me for a while I got completely swamped with it, it got to the stage that I thought, if one more person phones me and says that their mum or their dad is dying of cancer I'm going to crack up. I can't take it, its like an epidemic that's sweeping through the land and killing everybody I know. But, my friend who's a health visitor, who is a very practical, down to earth, kind of nurse person, you know, no sentiment or anything like that said, 'Don't be so bloody stupid' and she just kind of said quite bluntly: 'You know, it's the age you're at, you know, lots of cancers are age related and as you get older and your friends parents get older, they are bound to die of something so you're getting a bit, you are getting this out of proportion, of course your next door neighbour's father died of cancer at 82' she said, and I'm quoting her, "For god's sake he's 82, things wear out, things happen em, nobody is gonna live forever so its ridiculous to start thinking" but on the other hand she's wrong because it does affect so many people so it is a kind of an epidemic, not contagious, as far as I know. (Lisa 47, Affluent)"

Lisa's final point here about cancer being contagious is interesting. Although it was a throw away comment and Lisa is aware that cancer is not contagious, she is hinting at the uncertainty many people experience when trying to explain cancer. Many of these difficulties are raised again in the following section on aetiological explanations.

9.5 Aetiological Explanations

Before exploring aetiological explanations more closely, it is worth mentioning the language of causality. In scientific terms, cause and risk refer to different concepts. Cause refers to absoluteness, a definitive link between A and B. Risk, though, applies to a possibility, probability, a contributory factor or a potential hazard. Participants in this study did not make such semantic distinctions. Cause was used to describe not only aetiology but also risk. Participants were more likely to say 'pollution causes cancer' rather than 'pollution may increase your risk of cancer'. What they were actually alluding to was risk, not cause. Judgements about cause, in its truest sense, were made retrospectively, and links were made between cancers and known individual risk factors. Risk tended to be used more frequently in the context of overall population risk or in risk reduction.

The following section considers respondents' views about potential causes of and risks associated with cancer. These are grouped into behavioural factors, environmental factors, biological factors, and psychological factors.

9.5.1 Behavioural Factors

9.5.1.1 The embodiment of health.

Although an examination of health behaviours was not intended in the interviews, many of the participants strayed into discussing 'lifestyles', while talking about cancer risk factors. Moreover, participants were not asked specifically about their own behaviour though most volunteered this information. Participants were plain about what represented a healthy, and consequently, an unhealthy lifestyle. The models mirrored the widespread health promotion messages and the typical description of a healthy individual was a non-smoker, who ate a balanced diet, rich in fruit and vegetables. Alcohol

and exercise were to be enjoyed in moderation. For many, moderation was the key and the need to think about enjoying life, rather than being ‘faddy’ or over-anxious about health issues, was stressed, which echoes earlier findings (Backett 1992a; Lupton & Chapman 1995). This attitude has been found in other studies where limits were set on sensible risk-taking (Roberston 2006).

Well they don't want you to sit in your house - well, they want you to exercise for everything don't they - but you don't want to sit in your house and be frightened to eat this, that and the next thing, I really think its all things in moderation. (Kathleen 68, Affluent)

Some were keen to stress that they were healthy. In the following extract, Angus gives a detailed description of his diet, and emphasises that the lengths that he and his wife go to, to eat healthily are ‘crazy’:

I mean we exercise we take lots of fruit and veg, all wholegrain stuff, we don't overindulge in alcohol. I mean, I probably have two glasses of red wine a week Gavin's even less he doesn't, well he's a wimp, he doesn't like red wine, but red wine's better for you, so my wife and I take red wine. We don't junk food, we just don't junk food, eh we maybe have a fish supper once every six months, you know. We walk down to Helensburgh Pier and have a fish supper once every six, you know, that's so, we really eat healthily. We don't buy anything like mince out the shop we buy a piece of pork and I cut every piece of fat off it and I mince it myself, you know, we're really crazy. (Angus 54, Affluent)

There was some ambiguity regarding the status of smokers. While they were often immediately branded unhealthy, there were exceptions. There was a tendency for smoking to be excused, particularly amongst family members. This was especially true if other behaviours were deemed ‘good’. This echoes Backett’s (1992a) finding that ‘good’ and ‘bad’ behaviours were often traded and off-set against one another.

9.5.1.2 Smoking

As with many of the large scale quantitative studies that gauge awareness of cancer risk factors (Breslow et al 1997, Wardle et al 2001, Redeker et al 2009) smoking came up again and again and the link between smoking and cancer was universally accepted. Smoking inhabited a unique position. It was the only factor that was afforded the status of cause, in its truest sense. Smoking was

mentioned, unprompted, by all participants. Many associated smoking with most cancers, irrespective of site, which confirms Wardle et al's (2001) quantitative findings. For example, Janet, a nurse with experience of neurosurgery, made a definite link between smoking and primary brain tumours. Grace inadvertently made a link between childhood leukaemia and smoking:

Em, Laura and John both had cancer but they both smoked heavily and it was their wee boy that had died of leukaemia. (Grace, 68 Affluent)

Despite the unequivocal link between smoking and cancer, the fact that participants could cite examples of smokers who had never had cancer and non-smokers with cancer, especially lung cancer, led some to reassess their explanatory models. Some participants raised the idea that 'it must be more than cigarettes' as the following extract illustrates. Here, Phyllis speculates about the cause of her friend's colorectal cancer:

So it may well be that she was in a really smoky atmosphere that...It sounds in our conversation to you smoking is the answer, you know, that if everybody stopped smoking there would be no cancer where that seems to be what we're trying to put across. But there must be other things. (Phyllis 58 Affluent)

Rose was clear about the irony of her position with regards smoking but was quick to raise alternative causes:

But now here's me sitting smoking which I know causes it, I'm still smoking. I sometimes think it's genetic I mean I'm no educated enough to say whether it is or not but there's so many genetic things going about. (Rose 62, Deprived)

Colin, also a smoker, accepted the link between smoking and cancer but stressed that smoking was merely one, albeit important, risk factor:

I mean because you smoke doesn't mean that you do have cancer but there's no doubting the stats that say, which says that you're much more likely to get it at some stage and okay there are survivors and there are exceptions. Well I mean it's not a rule that if you smoke you die of cancer (Colin 61 Affluent)

Both Rose and Colin acknowledge the risks associated with smoking. Yet, they simultaneously were also keen to distance themselves from the risk. They may

not want to contemplate and adopt a stoical attitude (Scanlon et al 2006) or they wish to distance themselves from the stigma attached to smoking (Chapple, Zeibland & McPherson 2004).

So established were the links between smoking and cancer that lung cancer in a non-smoker was particularly unexpected:

.... Many of my relatives lived into their 80s and had been heavy smokers. So, my grandfather died of lung cancer, but again he was in his late 80s and he had smoked 60 a day since he was 14, so it wasn't really a great surprise that he died of lung cancer. So no, but I think that well, my mother-in-law, as well, ... she died of non-smoking related lung cancer and again, she had been ill and she had problems with her chest but we never imagined in any way, because she had never smoked. (Lisa 47 Affluent)

Despite offering anecdotes that highlighted cancer among non-smokers, and smokers who remained disease free, participants expected smokers to get cancer. They also accepted it when they did. Emily said of her mother-in-law, a smoker who died of breast cancer in her early 50's, 'she knew the risks'. Lisa talked about cancer patients continuing to smoke:

A few people that visited Alan in hospital, they'd say to me that they'd get annoyed with the people who were standing outside the hospital entrance, now it was the dead of winter and they were there with their dressing gowns on and some of them were obviously cancer patients, I mean you could see that, I mean some of them even had their drip stands with them, and they were still smoking and quite a few people who went to visit him commented 'Does that not really upset you when you have to pass through that fog of smoke and these people who still won't change their behaviour in any way, even when they are in hospital and they are so sick and yet they still won't give up cigarettes', you know' (Lisa 45, Affluent)

Chapple, Ziebland & McPherson's (2004) findings are echoed here, as participants introduce an element of personal culpability when talking about smoking, particularly when others are considered blameless:

It wasn't long after my dad had died that I saw this old boy sitting in Glasgow we were out to celebrate the 4th of July and em he was coughing and smoking and he asked for money for cigarettes and he'd got a beer and I said to myself 'why is he still alive and my dad's not' who led quite a good life. (Grace 63 Affluent)

Here Grace has decided that they 'old boy', by virtue of his behaviour has not led a 'good life'. This clear introduction of moral judgements will be returned to later in this chapter.

9.5.1.3 Passive smoking

A number of participants mentioned passive smoking, which was implicated in a number of cases:

My brother, he never even came into my mind earlier, he had cancer of the throat five years ago, five or six years ago so eh he stays in the middle east so he travelled over from Bahrain he flew into the UK, he paid privately but he was in an NHS hospital right and he got a lot of his lymph glands, part of his throat, his cheek, part of his tongue everything all taken away, there's only one gland going into his brain they all had been taken away but he was the doctors that see him said "How many cigarettes a day did you smoke?" he says "I've never smoked in life" and they said "You must have" and he says "I never smoked one cigarette in my life" and they didnae believe him so it must have been passive smoking. (Betty 61 Deprived))

The consultant said himself he was absolutely shocked (at the diagnosis of laryngeal cancer). And the only thing that my uncle put it down to is when he was a very small boy he had spent a lot of time with his father in pubs in the east of London that were really smoky environments. Em and that's the only, as far as he was concerned, contact that he had with smoking in any way. (Emily 37, Affluent)

As was shown in the previous chapter, celebrity cases of cancer had an impact of participants' understanding of disease. Roy Castle was synonymous with the dangers of passive smoking and Patricia extended his narrative to other famous people.

Well maist of the famous people when you think about cancer used tae go into clubs where smoking used tae be going on all the time and they say passive smoking is worse than normal smoking. (Patricia 62, Deprived)

Moreover Roy Castle's story was similarly borrowed to explain a further case of cancer. Here Emily talks about her husband's parents, both of whom had cancer:

but with the type of lifestyle that they had had when they were younger. His dad worked in clubs etc, he was a musician, so spent a lot of time in a smoky atmospheres, that kind of lifestyle they had at that point in time. (Emily 37, Affluent)

Peter was less certain about the effects of passive smoking:

Eh, lung cancer is quite often attributed to smoking. I think there is enough evidence to suggest that smoking is related to lung cancer. Whether passive smoking has an effect or not, I don't know. I suppose if you worked and spent 5, 6, 7 days a week in a smoky atmosphere it wouldn't do you any good. (Peter 67 Deprived)

9.5.1.4 Diet

Diet was seen as important for a healthy lifestyle, but unlike the certainty attached to the dangers of smoking, fewer direct links were made between diet and cancer. This is reflected in larger cancer awareness studies (Breslow et al 1997; Wardle et al 2001; Redeker et al 2009).

I mean I don't know what the risk factors are. Smoking versus a bad diet but I think generally when people think of cancer you think of smoking and not all the other rubbish that you put in your body including all the things in food that you probably don't think about. (Emily 37 Affluent)

Whether diet or exercise has got anything to do with cancer, I really couldn't say because I wouldnae say anybody that I, I really don't know anything about whether it's, I cannae think of anybody that I've heard of that did various things, you know, either did a lot of exercise or didnae do exercise or who drank a lot or who smoked, well smoke you hear about but I don't remember anything standing out in particular regarding diet. Could be I don't know. (Rose 61 Deprived)

Few specific foods were labelled carcinogenic, though some danger foods were identified, most notably red meat. Charles attributed his grandmother's longevity to her avoidance of red meat. He also highlighted the beneficial effects of fish and cited low levels of cancer in Japan as evidence. Other potential beneficial or protective foods were identified. A diet rich in fruit and vegetables was fundamental and there was widespread awareness of the 5-a day message. Antioxidants too were suggested. Obesity, as a result of a poor diet, was clearly acknowledged to be bad for one's health but only on a few occasions was it offered as a direct cause of cancer. The exceptions were a small number of cases of colorectal cancer in individuals judged to be obese. It should be stressed that at the time of the interviews there were a series of press reports that focused particularly on obesity and cancer.

Rather than diet per se, the impurities, chemicals and additives found in foods were seen as potential carcinogens. Kathleen talked about the apparent increasing incidence of allergies in children and provided the example of her granddaughter's allergy to genetically modified foods:

I buy organic, I buy quite a lot of organic now because one of the reasons is I don't want to have too many chemicals but another reason is that I have a granddaughter who is eight who can't eat, well she can't eat quite a lot of things she can't eat cherry tomatoes, but she can eat organic tomatoes and she can't eat coleslaw from any of the big supermarkets or Marks, but she can eat coleslaw from Iceland and the only difference I can see is that Iceland is GM free. I mean she ended up at the hospital with the tomatoes closing her throat and my daughter thought she hadn't washed them enough but the doctor said that the chemicals would penetrate the skin and you don't get that with organic. You are allowed some chemicals with organic but nothing like what we get in ordinary food. So the fact that just that amount of chemical, which the government tells us is safe, for her and I have hay fever allergies but not food allergies but for somebody to be able to have food that doesn't have that minute amount of chemicals but can't have it if its got it then I think maybe none of us should have those chemicals. (Kathleen 68 Affluent)

Pesticides too were mentioned. This echoes Baghurt, Baghurst & Record (1992), who found that more than half of their survey respondents believed that pesticides in food were extremely important risk factors for cancer. A handful of participants in this study extolled the virtues of organic foods. The inference was that tampering with food must be harmful.

I'm a great believer in organic a lot of things because nobody has ever, as far as I'm aware done research into all the fertilisers that were used 20, 30, 40 years ago in the ground and what affect they have on people so I try to buy fresh and whatever (Julia 65 Deprived)

Equally, the reliance on convenience foods and the prevalence of processed foods in the modern diet were thought to be detrimental to healthy living. Although this was not always discussed specifically in relation to cancer it does tie into the ideas of cancer as a disease of modernity (Herzlich 1973; Salant & Gehler 2008). Many participants, especially older women, lamented the loss of cooking skills among the younger generation. Often this was described as a particular problem in areas of deprivation:

“..... With diet, I know what people who think they’ve got no money do. You see them , they go in the shops, and I see them they buy pies and all sorts of things and they could make cheaper healthier meals for less money if they got taught. Now I got cookery at school and its still with me and I still cook my mince and my stew the way that my cookery teacher taught me and I worked in the kitchen with my mum because I was the eldest and I think they should be getting back to basics and making pasta and making things go further and things like that and I think that a lot of people don’t eat things because they don’t know how to get it and they don’t know how to cook it but I don’t honestly know if a diet would stop people taking more cancers. I think some part of it could be going back to when they used all the different fertilisers but then what would account for when the really young taking cancer (Julia 65, Deprived)

9.5.1.5 Alcohol and Exercise

Both moderate exercise and moderate alcohol were typically located in the ‘healthy’ model’. Although exercise was clearly associated with health, lack of exercise was rarely offered as a risk factor and many thought that exercise was largely irrelevant. As Murray states:

I think it plays a very, very small part, if any, in cancer. (Murray 83 Affluent)

Interestingly while excessive alcohol consumption was linked with unhealthy individuals, abstinence was also to be avoided. A number of participants thought that red wine especially was beneficial for health. The following extract exemplifies the strength of mixed messages surrounding alcohol when some document the beneficial health effects of alcohol (White 1996; Chadwick & Goode 1998):

A couple of weeks ago there, there was a thing out about heart disease or cancer or something, in the papers, I mean nearly everything is bad for you I mean you may as well throw in the towel. I mean I always remember reading in the paper, Jock Stein the great Scotland manager died of a heart attack and people in the papers were saying how could that happen to Jock Stein? He didn’t smoke and he didn’t drink and he was an active man. And, there was a doctor in the paper, whatever you call these doctors in the paper, said, that was probably the thing. He would have been better off if he had taken a half a night ... (Andrew 57 Affluent)

Some were aware that made links between alcohol and cancer, specifically head and neck and gastrointestinal cancers. Kathleen attributed a close friend’s

recent colorectal cancer diagnosis to alcohol. This was the exception and few raised alcohol unprompted. Though on reflection some supposed that it might be a risk factor, as Emily suggests:

Just same the principle, it's still putting a toxin in there so yes but it's not something that I would immediately volunteer to be attributable to cancer. (Emily 37 Affluent)

9.5.1.6 Sun Exposure

Like smoking, sun exposure was an accepted cause. Gary echoed Ness et al's (1999) claim, believing that the sun is 'good for you'. Unlike smoking, sun exposure was not raised unprompted by all participants. Rose provided the example of her brother-in-law who had skin cancer and attributed this to excessive sun exposure as a child. Others talked about sun safety messages, and how these were at one time little known:

Well I thought the girl with skin cancer eh she never, ever used any lotions but I'm going back she's dead now over twenty years, right. And she was in her forties as I say she was about forty-six and we didnae know about creams, you know, and she was a sun worshipper. She went to, she had a daughter was married to a boy in Tenerife, I couldnae remember the place, Tenerife, and they went there for six months at a time. (Betty 61 Deprived)

Yet, the understanding of safe sun 'use' was not universal, as the following extract demonstrates. Lorna provides the narrative a close friend diagnosed with malignant melanoma:

Lorna : Recently she developed this thing on her ear and all I kept saying, "That's changing you better go and see about that" and she says "I've got skin cancer on my neck. ... So I don't think, no she disnae abuse herself, she disnae drink, she disnae smoke but there's a big family thing there.

I: Uh huh, and what about other risk factors for skin cancer like sun is she a....

Lorna: Oh sun uh huh, no she isnae a sun worshipper, I mean she certainly does em she gets very burnt when you go on holiday. (Lorna 57 Deprived)

9.5.2 Environmental Factors

Participants discussed a wide range of environmental factors that may be linked with cancer. Most knew someone who had previously worked in a hazardous environment and with toxins. Elsie's husband, who was a smoker, had recently completed his cancer treatment yet she attributed his head and neck cancer to his habits at work. The following extract demonstrates how information from many sources is inducted into explanatory models. It might also be inferred that she sought an aetiological explanation other than smoking, which is known to attract stigma (Chapple, Zeibland & McPherson 2004):

I'm inclined to have wee thinks to make up my mind I might be entirely wrong. He was a Commercial Artist and away back, well he used to take his paintbrush into his mouth and suck it to get a nice point to do the lettering and I thought, I think I'd read something or I'd seen it on the television there was a factory I think somewhere about Dundee, I think it was clocks they made, and the faces to make the face of the clock or the numbers luminous the women there who painted the dials had radioactive paint they used and quite a lot of these women apparently died of cancer. (Elsie 62 Affluent)

Many participants cited work hazards. Asbestos was raised a number of times. For example, Grace talked about her brother's exposure in car plants and subsequent death from asbestosis. Lisa, whose father worked for British Coal, talked about the dangers faced by miners and provided the example of her father-in-law who had died of lung cancer and had posthumously received a compensation payment from his employers.

Nobody that I was in school with, or very few of them have parents who are alive now because their fathers all died in their 50s of lung cancer, of emphysema or pneumoconiosis because they worked down pits and the result of heavy industry (Lisa 45 Affluent)

Angus, a former fire fighter, highlighted a number of cases of cancer among colleagues. What the extract shows is an uncertainty about exposure risks and links to specific cancer sites:

I've lost some workmates and the only common denominator is that we were all senior officers in the fire service and when we joined breathing apparatus wasn't used readily it was the exception rather than the rule. If you go into a fire you're breathing in hydrogen sile and God knows what else. So all my thirty years in the fire brigade

I just breathed in toxic fumes and they were the same. So probably on the work side the people that I've lost at work through cancer that may have been ... but none of them were lung cancer it was all other places but I don't know how cancer works, you know. (Angus 54, Affluent)

My dad [died of bladder cancer] had worked in a laboratory for a lot of his life and had to deal with formaldehyde a lot. And the cause of cancer particularly applies (Laughs) so that was kind of where that one was so I sort of knew or that was believed to be the cause. (Clare 41, Affluent)

As well as individuals' working environment the impact of industrial practices on the wider population was also raised. Pollution, nuclear plants and sites, chemical factories and electricity pylons were all introduced into the discussion. The following extracts show that respondents were fully aware of the implied connections between environmental factors and cancer. Yet, not all were convinced of the link:

I think there is a link with cancer certainly a link between cancer and radioactivity, anybody who works anywhere near Hunterston or Sellafield or even the North of Scotland up the top there as well. You probably find there's linkage to cancer, even cluster cancers, if you like (Charles 74 Deprived).

I mean I've got another friend who lives in Canada now whose father died of bowel cancer many years ago. But she was brought up .. Oh, somewhere down in Ayrshire, near the ICI plant and she's lived in Canada for 20 odd years but her dad died of bowel cancer before she went to Canada and then her mother, in the last couple of years, I mean she was 77, I can't remember what type of cancer it was to be honest and she was saying 'Oh, I know so many people whose parents have died of cancer, who come from that area, I think its got something to do with the ICI plant, they must have been polluting the atmosphere'. So. I'm not discounting that, there may be some factor like that, there may be clusters like that and people do, I mean you'll know, loads and loads of research on these things to see if there are patterns and clusters but I mean what I said to Jenny at the time was, "You may well have a point but can I also say to you that I know an awful lot of people who didn't live anywhere near an ICI plant and whose parents didn't smoke and you know have led quite healthy lives and who still get cancer". (Lisa 45 Affluent)

I was aware there were concerns (about cancer 'clusters') but I'm also aware that I have enough training and stats to understand that you can do a lot of things with stats. I mean take the MMR, I think for example absolutely shite, right I mean there have been more damage done to more children by whoever irresponsibly raised that flag in

*the first place. And, you know, how the bandwagon developed so that I mean Doctors were actually saying “Okay well we’re no going to do it”, you know, and f***, I mean, unbelievable. But I mean point at the electricity pylon that’s what I was going to say the electricity pylon stuff and mobile phones and mobile phone masts and all that. As I understand it there is as yet no hard scientific evidence, which says either mobile phone use or mobile phone masts do generate cancer hotspots..... But if you went through them carefully the actual proven, well there’s no proven instance or causal relationship I mean you can’t get that from just eclectic stats you can’t prove a causal relationship. But there are so many reasons for, you know, for clusters of cancer hotspots and I mean the geology of the event is a major factor for example or so I understood. That, you know, there are types of rock in which, you know, if you’re in constant contact and you live in a house built of granite, for example, well granite is radioactive. (Colin 61, Affluent)*

The above extracts show that environmental factors were usually synonymous with cancer ‘clusters’ or ‘hotspots’. Support for the presence of clusters was mixed and Colin provided a rational scientific reason.

A number of participants mentioned the dangers of mobile phones and the possible connection with brain tumours. Two participants also reported that they had quickly dismissed friends/colleagues warnings that carrying phones in their breast pocket because they ‘might give you cancer in your heart’.

Well, they say that mobile phones give you cancer and some other reports say that there is nothing to prove that a mobile phone has actually been the cause of a case of cancer. So again it’s what do you believe? (Rona 32, Deprived)

Environmental risks associated with cancer are as likely to be the subject of media coverage as many health promotion messages (Trumbo, McComas & Kannaovakun 2007). The extracts above demonstrate the salient impact of the mainstream press. All of the environmental hazards featured more frequently in interviews than behavioural factors like exercise, and to a lesser extent sun-exposure. Nevertheless, participants were more sceptical about the importance of environmental risks and some acknowledged the ability to manipulate statistics to produce the desired message. Supposed cancer clusters do have an impact. Guidotti & Jacobs (1993) found that residents in a community much publicised as a cancer cluster changed their health related behaviour.

9.5.3 Biological Factors

9.5.3.1 Age

Participants generally recognised the connection between cancer and age, which is at odds with findings in other studies that show that age is poorly recognised as a risk factor (Wardle et al 2001; Keighley et al 2004). Increased life expectancy was thought in part to explain the rise in cancer incidence. Yet, there was a tendency towards a curious paradox in discussions about cancer and age. Many expressed the belief that cancer in the elderly did not represent the aggressive disease or the painful death normally associated with cancer:

*I wonder the younger you are I think the speedier the tumour grows
(Kathleen 68, Affluent)*

Older people were thought more likely to live with cancer for longer periods of time, and cancer was unlikely to kill them. One participant, Barry, reported that a family-friend, a nurse, had declared that ‘virtually everybody in their 80’s had some sort of cancer’. His story then shifted focus slightly as he told of an elderly friend, who was 93, that he regularly went swimming with. He had noticed what he thought were suspicious moles on his friend’s back but had chosen not to raise this because of his friend’s age:

Barry: As I say we go swimming, well his back is covered in brown blotches, now he’s 93. Who is worrying at this stage? But I don’t know what they are, I don’t know whether I’ve seen them probably or whatever or nobody has pointed them out to him but what are they?

I: Does he have someone else at home?

Barry: No.

I: Because quite often with skin some people only get a diagnosis because they have somebody else that points out that there is something there, I mean I’m not saying that you should therefore suggest that but

Barry: A younger person you would. (Barry 74, Affluent)

Lisa adopts a similar position when discussing her aunt’s breast cancer:

My own aunt had actually died, she was diagnosed with breast cancer but um, again it sounds a bit odd to say but she was in her mid 80s and she smoked very heavily all her life so she was kinda dying anyway, you know she had lots of other illnesses and she had been in and out of hospital and eventually someone said 'Oh by the way, she's got breast cancer as well'. So it was like, 'Oh God, not that as well', but em, in a sense, you know somebody said to me at the time, you know she's not gonna die of it at that age, she'll die of other things (Lisa 45, Affluent)

Cancer in older people was more readily accepted. Older people were often judged to have 'had their life'. Some participants used phrases like 'you've got to die with something', hinting that among the elderly, cancer was not so tragic and more palatable. Betty who had said that her mother had had her life went on to say:

Although it was a terrible death for my mother, her actual death bed was excruciating to witness. (Betty 61, Deprived)

9.5.3.2 Hormones

A number of women talked about the hormonal causes of breast cancer. One talked about the benefits of breast-feeding but as this extract reveals, disconfirming evidence had caused her to re-evaluate her beliefs:

I've had four friends, sorry, I forgot about my other friend in Edinburgh em, I always thought that if you breast fed you had less chance of developing breast cancer and the three in (local community) did not breast feed - not because they didn't want to but because they couldn't and my friend in Edinburgh, she breast fed and she developed breast cancer so my theory is sort of out the door in that respect (Jessie 68, Affluent)

9.5.4 Psychological Factors

9.5.4.1 Stress

Although Pollock's (1988) in-depth study of the lay perspectives of stress found that participants made few associations between cancer and stress, stress has been linked with cancer in other studies, both quantitative and qualitative (Blaxter 1982; Wardle et al 2001; Scanlon et al 2006; Redeker et al 2009) though the relationship is often thought to be tenuous. In this study stress was rarely cited as a specific risk factor. Phyllis mentioned stress and then dismissed it:

Well you don't know I mean I think stress too has something to do with cancer and yet when you see babies and young people getting it you wouldn't imagine that they would lead stressful lives (Phyllis 58, Affluent)

It was however thought to be a cause in a handful of individual cases, particularly when other potential, usual causes were thought lacking. Clare believed that perhaps 'emotional issues' were responsible for her mother's cancer because she didn't fit the typical cancer profile:

My mum's breast cancer I guess that was more of a surprise, a big surprise because she was a very healthy person, very fit active healthy, good diet I mean all the boxes you think you should ticking so that was a big shock. But I suppose in retrospect em although my sister and I have looked at it and thought there was a lot of emotional issues and wonder whether there wasn't a psychological element going on there. (Clare 42, Affluent)

Although both Patricia's parents were smokers, she was certain that her mother's cancer had been triggered by a single traumatic event, a mugging and the cumulative effect of many years of domestic abuse:

".... she was pretty bad wae the last one(beating) she got and it was just efter that they found oot she had the cancer." (Patricia 62 Deprived)

Later in the interview Patricia questions the role of stress in the development of her father's cancer:

" Maybe it [stress] could have, it could have but then my dad didnae have the stress, well maybe he had the stress, he'd be stressed he'd actually got taken intae a wee room when he was on his own and telt my mum had the cancer when he was attending for his heart. And he was in shock wae that so in that way maybe although it was a few year later before he contracted cancer. I don't know." (Patricia 62 Deprived)

The absence of stress or happy lives was postulated as reasons for avoiding cancer. Murray attributed all cancer to smoking, although both of his parents had lived long and escaped cancer. His explanation for this is bound up with many things, including a happy life:

Luck, I think so, I can't think of anything else, both lived happy and fulfilled lives, I think that may have been a factor but I don't know.

Um, my mother was a very, very active woman, my father much less so (Murray 83 Affluent)

9.5.4.2 Personality

The apparent centrality of personality factors in cancer narratives and the need to remain hopeful and positive is ubiquitous (Balshem 1991; Blaxter 1982; Ehrenreich 2009). Many of the individual cancer stories retold in the media introduce personality, generally in terms of ‘fighting spirit’ (Seale 2001a, 2001b). If personality is so important in fighting disease, is it also relevant in hosting it in the first place? Participants typically dismissed this proposition. Yet, this did give way to some discussion of pessimists, or worriers possibly being more prone to disease. Elsie concluded that a tendency to worry was the only common feature in two of her friends with cancer:

Two of them I can think I would say are the type that sort of worriers, you know, one is particularly pessimistic (Laughs) I would actually say I don’t know whether that’s got anything to do with it or not. (Elsie 62, Affluent)

Much of this is related to notions of morality, and the importance of not ‘lying down’ to disease (Blaxter 1982) and perhaps the feeling that it is best not to talk about the disease, for fear of ‘inviting it in’. Activity and hard work are thought to be important protectors against disease (Balshem 1991), cleanliness too is important. Barbara, when talking about people ‘that you least expect’ to get cancer, reported her shock on hearing of a colleague’s cancer diagnosis because she had always been ‘so well turned out and pristine’, again hinting at the importance of morality.

9.5.4.3 Genetics and familial factors

The identification of disease specific genes has elevated the gene to the status of ‘cultural icon’ (Nelkin & Lindee 1995). The discovery of BRCA1 and BRCA2 genes linked with breast and ovarian cancers has led to a fixation with familial element in cancer (Henderson and Kitzinger 1999) Knowledge of cancer genes is widespread and most participants believed there to be a familial risk, specifically for breast and colorectal cancers. Grace, whose husband died of colorectal cancer, told that her GP had said that her husband had “inherited cancer, though he couldn’t prove it”, and recommended that her sons be

screened from the age of 40 onwards. Others were aware of the links with breast cancer and a number of female participants whose relatives had had breast cancer were clear that the risk was associated with a certain type of breast cancer thought to appear in younger women. None placed themselves at an increased risk of cancer because the cases in their families were 'different'.

More generally, the participants extrapolated the family links to all cancers. Participants typically talked of cancer 'in the family', irrespective of cancer site. Identifying diseases as family traits has been explored and reported on previously, especially in the west of Scotland (Hunt Emslie & Watt 2001). One participant described how her friend, recently diagnosed with skin cancer, felt it was inevitable that she would get cancer because of her family experience:

Her mum died wae cancer, her dad died wae cancer, her mother's four sisters died of cancer, her father's two brothers died of cancer, Her own brother died of cancer at forty-seven and she's been saying for years, she's had a lot of gastric surgery this girl, and she's been saying for years "It'll definitely get me I'll no get away wae it, it will definitely get me." (Lorna 57 Deprived)

This was not uncommon. A number of participants knew of families with many examples of cancers in different sites and thought this must be more than coincidence. In the following extract the Josephine recounts the story of her neighbour:

Josephine: Well there's a lassie up the next close ... there's been a whole lot of members of her family have died wae cancer and her man's really worried and he's wanting her tae go and get checked. But just like everything else you put your heid in the sand and say 'Naw, no me' but I think she's feart tae go.

I: Uh huh, how old is she?

Josephine: She's in her fifties. Noo, there's been one just died wae, em, breast cancer, bowel cancer, eh Hodgkin's., Aye, so it's all different cancers it's no just one type of cancer.

I: But that's all in her family?

Josephine : That's all in her family.

I: And do you think her man's right to be worried?

Josephine: Aye. Well I would think I'd want tae be checked oot as well, know what I mean?

For some participants the presence of a familial element was thought to be at least as important as lifestyle factors in determining cause:

I eh ... (pause) I think there is a very strong hereditary strain in cancer and people who don't have that- If someone is suffering from cancer and I don't know them well - my first two questions would probably be - is it their lifestyle or is in the family? (Andrew 57, Affluent)

Equally, cancer was thought to 'not run' in families. Some participants pointed out that cancer was not in their family. Often this was qualified by suggesting that in their family they had an alternative 'problem' like 'the heart' or cholesterol. Implicit in these statements was that a family could have only one serious illness although different illness could appear on each 'side' of the family (Hunt, Emslie & Watt 2001; Sanders et al 2007). The following extract shows that Gary, despite his father's prostate cancer, did not see his family as a 'cancer' family:

As I say, ma dad had prostate cancer eh I was thinking about his brothers dying nane of them had cancer. One of them has got Parkinson's just noo but apart fae that ma Ma's side is pretty healthy. They've got Alzheimer's on their side, you know, ma Ma's got that the noo she's in a home eh but cancer disnae seem to be the one but apparently ma Dad's family's got heart trouble, you know. So I think I've got a choice between heart or (Laughs) Alzheimer's (Gary 3, Deprived)

Not all participants were convinced that cancer was hereditary. Interestingly those with close family experiences of cancer did not think that this put them at a higher risk than any other individual. There are two possible reasons for this. First, it might be that because of their experience they have more knowledge about specific risk because they have been confronted with cancer (Beebe-Dimmer 2004). It might also be that wish to distance themselves from heightened risk, much like cancer sufferers wish to distance themselves from culpability (Linn, Linn and Stein 1982).

9.5.4.4 Triggers and the dormant gene

As well as familial genetic links and hereditary factors, participants introduced and understood genes in another way. Aetiology was attributed to genes but this was distinct from family patterns. Articulated in numerous ways, many participants asserted that cancer was explained by the presence of a faulty or cancer gene. This idea is present in many of the studies reviewed in this thesis over many years and appears to be an enduring belief (Cornwell 1984; Calnan 1987; Mullen 1994; Scanlon et al 2006; Goldman et al 2008). For some participants, this was apparent in everyone, while others believed that it could be found only in certain individuals. The presence of this faulty gene was not associated with familial links. Rather the cancer gene was innate and appeared by chance. In order for cancer to then develop the gene needs to be activated. Activation requires a trigger and triggers could take many forms. Psychological distress, either as the result of a single event or repeated long-standing abuse, could act as a catalyst. Physical events too were implicated with a knock, another illness or surgery being offered as possible triggers. Non-activation explained the absence of a cancer event. Angus offered the theory of a dormant disease described cancer as a ticking time-bomb and provided the following analogy:

Or is it, I mean, is it just a time release thing, you know, like you can use the time release fertiliser in your plants, your pot plants you stick it in and over time it slowly lets out the fertiliser. Is that in our system where the cells work properly on a time release system and then when it gets to a certain time it's just says 'oh I don't want to work properly anymore' and then it produces the cancer. (Angus 56, Affluent)

9.6 Cancer: a disease of modernity?

Participants in this study demonstrate a changing perception of cancer. Often, the change had been dramatic. For most this was a temporal change, a natural evolution that keeps pace with scientific advances. For others it was experiential, a forced change needed to acknowledge a new reality. Regardless of the reasons for the change it is clear that cancer does, at least on the surface mean something different now than it once did. Once universally stigmatised, cancer assumed a largely 'folk' nature. It meant death and few were aware of why it happened, what caused it and often who had it. In the early 21st century

cancer is a public disease, the subject of much media attention and research. Information about cancer is readily available, knowledge of cancer is improving constantly and some participants felt sure that most forms of cancer would one day be cured.

Yet, this modern view of cancer extended further. Much like Herzlich's (1973) participants almost 40 years previously, most thought cancer was now more common; being described as rife, epidemic, and as 'common as the cold'. Participants thought that incidence had genuinely increased rather than believing that the increase was an artefact of openness. Again echoes of Herzlich's work can be found in explanatory models. Nearly all participants talked of pesticides, food additives, pollution, mobile phones and phone masts, and electricity pylons in relation to aetiology. All of these are features of modern living. Gary talked about the now widespread use of disinfectants, rendering immune systems powerless in the face of modern germs, and claimed that those in his father's generation had a stronger immune response. Caroline talked about the potential iatrogenic effects of modern vaccines. Such discussions merely represented hypothesising but were, in part, buoyed by the idea held by many that, 'if you look hard enough, everything causes cancer' (Niedereppe & Levy 2007). The 'everything' however is synonymous with social changes: mobile phones, pollution, pesticides, genetically modified foods, convenience foods. The negative impact of modernity on health has been found elsewhere (MacFarlane & Kelleher 2002; Salant & Gahler 2008). Moreover, it is the availability of knowledge in the information age that heightens this awareness. Cancer then has shifted from a largely folk model of disease where little is known about cause or cure to more sophisticated model that incorporated the dominant bio-medical and scientific model.

9.7 Narratives and metaphors as a means of obtaining understanding

9.7.1 Use of narrative

Research in the area of psycho-oncology often seeks to describe and explore the patient and carer experiences of various aspects the cancer journey. It is customary for such experience to be recounted in the form of stories or

narratives (<http://www.healthtalkonline.org>). Narratives though are not the preserve of the patient or carer. As previously noted, participants frequently used narratives or more accurately a series of narratives to provide contexts for their views and beliefs. Narratives were offered as evidence. Some, depending on the proximity to the patient, were retold in great detail others were less comprehensive. Yet, each interview holds at least one narrative that is used to frame their explanatory model.

Clare had recently dealt with the death of both her parents and her close friend and admitted that she had re-assessed her pre-conceptions. She now believed cancer represented a random, unexplainable event, and illustrated this through the following story:

I think more and more now I'm just accepting that life is just a random set of events and some people I mean the surprising thing, I mentioned that neighbour of my parents, Jeff he was a heavy smoker and he actually always, he was one of those people who sort of looked ill, he had a bit of a pallor. Now, even though I can't remember when he was diagnosed with cancer but I know my parents knew he had cancer and was fighting it long before either of them were diagnosed with having any kind of illness and he outlived both of them (Laughs). So I think I mean there's like, a lot like that because I just think cause, you know, that's it it's a completely (sigh) random, strange disease that affects people totally differently. Some people can fight it for ages, some people it crashes incredibly quickly and I don't know how you make sense of that. (Clare 41 Affluent)

9.7.2 Use of metaphor

Metaphors are common in cancer narratives (Sontag 1978; Lupton 1994). Participants here are no different and many used metaphors when talking about cancer. The most liberally used metaphors were combative, which is not surprising given their dominance in the media (Seale 2001a, 2001b, Clarke and Everest 2006). Lisa explained why she felt that military metaphors were appropriate:

I think that there is a grain of truth of it being a battle because it certainly is, you know when you are undergoing treatment and chemotherapy and whatever, there is a, I'm maybe putting myself in the place of someone who has actually suffered it but there is,

people I know do tend to see it in terms of them against the disease and they do sort of see it as a battle (Lisa45 Affluent)

Josephine recounted a conversation with a friend about a mutual friend's recent cancer recurrence. They referred to cancer in human terms, giving it personality characteristics, describing it as devious. Other participants described cancer as mean. Metaphors were also used to illustrate the affect that cancer had on sufferers. It was common for participants to use terms like 'eating away' or wasting away. Some metaphors went further, Peter's entire explanatory model was based on a metaphor:

I liken, and this is just a personal, simplistic explanation. I liken cancer to growing plants, I'm quite a keen gardener and some seeds germinate, some don't, some grow better than others some live longer than others and some sort of wither away. I see cancer as sort of withering away of the cells and we are all gonna die at some point anyway. Cancer, is a sort of, if you like, accelerated dying. (Peter 66, Deprived)

9.8 Challenges to meaning and understanding

Far from being poorly understood (Scanlon et al 2006), participants appeared to know and understand a great deal about cancer. Though the views expressed in the interviews were not always biomedically accurate or expert, they did display a thoughtful approach to the formulation of explanatory models. Yet there were aspects of the cancer experience that defied such logic. Prominent among these were childhood cancers and the role of luck or random events.

9.8.1 Childhood cancers

Among the most challenging aspects of understanding cancer was cancer in children. Participants often spoke about cancer in children in an entirely different way to adult cancers. Childhood cancer represented the unthinkable and the unexplainable. Few participants were close to a child with cancer and one participant, Emily, surmised that not having to confront or think about it obviated the need for explanation. This confirms the ideas held in the psychological notion of 'availability heuristics' (Tversky & Kahneman 1981; Kapodi et al 2003), which claim that ideas can only be formed from the information available. Yet, the lack of experience made it no less frightening

and many participants referred to childhood cancer as particularly ‘mean’ and ‘cruel’.

Childhood cancer was most frequently linked with potential environmental hazards and many participants saw cancer clusters as synonymous with childhood cancers. A number did question maternal behaviour and proposed that children were exposed in to carcinogens antenatally:

Well, you don't know, what the mother's been doing during the pregnancy, I just wonder sometimes if the mother has been doing things that she shouldn't do during pregnancy, you know have they come in contact with anything, I mean you just don't know. Because I have never questioned anybody and I really don't know anybody who has had a child that's had cancer, so I really don't know. (Jim 64, Affluent)

What was striking about childhood cancers was the explicitly raised assertion, frequently repeated, that children simply did not deserve cancer. As Jessie's borrowed narrative shows: repeatedly:

Oh .. children (sighs) well .. I know that my friend was having radiotherapy and there was a little one of three and she just thought 'what harm has she done anybody?' I mean children don't deserve it and I don't know why they get it, I really don't ... (Jessie 68 Affluent)

The logical corollary of children not deserving cancer is that some people do deserve cancer. Moral judgements were introduced into discussions about children, and this will be returned to in the next section.

9.8.2 Luck or random events

All participants alluded to the role of luck, though not all were willing to elevate its importance:

Well I don't want to use the word luck so it's got to be genetic; the cancer gene isn't there for it to be started up. (Barry 74 Affluent)

Luck was often the last explanation offered when all other plausible or logical positions had been exhausted. The presence of cancer in those adopting ‘good’ behaviours and the escape of those engaging in bad behaviours served to emphasise the significance of luck. Irrespective of the terms used, whether luck,

random events, or fate, there was an overwhelming view that behaviours can go some way to reducing risk but there is nothing that can guarantee that any individual will or can escape cancer:

I don't think that if you are healthy that you necessarily escape things. I don't think that there is a rule you know because you're healthy you don't get anything bad happening to you, I think ultimately, its just the luck of the draw, I suppose. (Rona 31 Deprived)

9.9 Morality

The stigma surrounding cancer, apparent in many of the participants' formative years, was attributed to fear of the unknown. Cancer equalled death, which only strengthened the taboo. Today the openness around cancer and its causes has led to a shift in the source of shame. Health promotion messages place the responsibility firmly with individuals (Chapple, Zeibland & McPherson 2004). The pervasiveness and profile of such messages leave few able to discount the risks or claim a lack of awareness when opting to engage in risky behaviours. This was not true a generation ago when the ill effects of risky behaviours, like smoking, were not fully realised. The emphasis on individual responsibility renders those that ignore advice behaviourally immoral. Peter captures cancer's socio-cultural status:

I don't have any hang ups at all about cancer I don't see it as a stigma the way some people do. It's not something you get by misbehaving or doing something wrong. Your lifestyle may contribute to it, and then again may not and people say that smoking causes cancer but people get lung cancer who have never smoked in their life and how do you explain that? There are all sorts of ailments and all sorts of things can be attributed as a cause of cancer but its not anything to feel eh, that you've done something wrong. Yet, a lot of people won't talk about it, won't discuss it and it can hit anybody and it doesn't matter whether you are rich poor, young or old or whether you live a healthy lifestyle or don't. I suppose more people who don't live healthy lifestyles are at risk and the statistics would show that if you have a low income and a poor diet and you drink too much and smoke too much and live a riotous life, you're more likely to get cancer. But there's no guarantee that anyone will or won't get cancer. (Peter 67 Deprived)

Moral judgements about behaviour feature strongly in many interviews, often explicitly. In the following extract Jessie is searching for possible explanations

for cancer events, and although she referred directly to heart disease and strokes, her view hints at her broader moral position on behaviour:

Again, stress of every day life and work, that can cause strokes and heart but that's not to say that these people are leading a bad life. They're not smoking, drinking and going out at night and what have you but they've got a lot of stress of work and that can cause People that are not in work that have no worries at all (laughs) they seem to be the ones that are getting away with everything they don't have to worry about the heating, the lighting and they're the ones that drink and smoke and what have you. (Jessie 68, Affluent)

This was not the only reference to worklessness; in the following extract Jim draws comparisons between drug-misusers and the working population and comments on fairness:

Junkies, they've no veins to inject they're into in here, they're into their legs right down and they're still injecting they're still getting the treatment and they're still alive and there's other folk they're no doing any harm they've worked all their way through life and they're away, you know. But that's just, life isn't it fair. (Jim 64 Affluent)

The inference here is that some people do not deserve cancer. Echoes of this notion are found in discussions about childhood cancer where the overwhelming assertion was that children do not deserve cancer. If children are regarded as undeserving, is the corollary of this that some people do deserve cancer?

9.9.1 Who deserves cancer?

Participants did not openly suggest at any point that individuals deserved cancer, although those that were judged to have behaved badly or 'abused' themselves were hinted at frequently. Cancer, as has been shown elsewhere in this chapter, is understood to be an unfair and fundamentally tragic life event. If children are undeserving because of their innocence, are the guilty deserving? Who are the guilty? The emphasis on individual behaviour in aetiology has elevated health choices to the status of moral positions. By engaging in 'bad' behaviour individuals have rendered themselves susceptible to cancer and ultimately to blame for their illness. Yet for some this went further than health behaviour. Lisa described her anger at her husband's cancer diagnosis, particularly as he had done the 'right' things:

Lisa: I said in relation to (husband), I was bloody mad, 'Its not fair, why did that have to happen to him, he's a good person, he's never done anything to deserve that so, you know that made me very angry

I.....You said there, you know you would get quite angry and say that he didn't deserve this, does that suggest that some people do?

Lisa: No, (pause) no that's it, I think its not a rational way to think, no you're quite right (laughs) I suppose it would be a really nice world if people that abused children and were really horrible got cancer and died, that would be lovely but I mean I know that's not the case, but whether or not some people deserve it.

I I just mean ... earlier on you said, people, they lead good lives and yet they get cancer

Lisa : Yeah, some people do (laughs) Uh huh there are people who do all the wrong things and I don't necessarily mean morally, I mean behaviourally, and seem to get away with it. (Lisa 45, Affluent)

The discomfort felt when the natural order of life is disrupted is evident in the following extract. Jim and Phyllis, a couple interviewed together, talk generally about illness and they move quickly from discussing age to behaviour. Both in the context of morality:

Jim: My sister died at eighteen and I was very bitter, very angry, very bitter, very anti-church, anti-Christian type

Phyllis: There's no answer to that.

Jim: No, I know there's no but what I meant was it changes your outlook and your attitude tae things, you know. You're saying young people go and die of cancer. Why has that young person gone and the old granny whose had a good life and still there, you know.

Phyllis: Or worse than that people who do really bad things. Those that are in jail locked up (Jim 64 & Phyllis 57, Affluent)

9.10 Degree of difference or similarity in accounts of meaning and understanding

What was striking about the data generated from the interviews was the similarity in accounts. Although participants were of different ages, genders, socio-economic backgrounds, and had different personal and professional experiences of cancer their views were typically homogenous. Ordinary views of

cancer, even amongst those with a close experience of cancer, are dominated by a combination of media publicity and health education messages. Experiences too, despite individual nuances were remarkably similar. Even within single accounts participants provided a number of examples that confirmed their view of cancer. Angus described his brother who died suddenly of pancreatic cancer, and of another brother suddenly diagnosed with mantle cell, and this fixed his view that 'you never know when you have it (cancer)'. Subsequent narratives generally served to strengthen his evidence. This model appears again and again. As has been shown elsewhere in this chapter experiences provide the storyline for explanatory models, and they are compared with established bio-medical explanations. All of the explanations for cancer that might have been anticipated were explored during the interviews. Most were introduced unprompted by the participants. The relative importance of causal factors varied among participants but this was not socially patterned.

Beliefs about, and experience of, health is socially patterned and some of these patterns are mirrored in this data. Women were over-represented in the sample and they also had more experience on which to draw. As such women tended to offer more information and have more complex explanatory models. This may simply reflect their experience. If a male participant had a close personal experience they too had much to offer. Males relied more heavily on scientific explanations and most believed that everything could be explained. Males were most likely, for example, to be sceptical about clusters. The youngest respondent certainly had given the least thought to cancer, yet the same is true of the eldest, probably because neither had little direct experience of cancer.

9.11 Chapter Summary

In this chapter a detailed description of participants' explanatory models of cancer have been outlined. The findings show that while the fear and dread associated with cancer is paramount, there have been very real changes during the second half of last century. Nevertheless, cancer continues to mean fear. For most cancer means tragedy, though this is most likely the result of media portrayal rather than personal experience. All participants were aware of someone who was now 'living with cancer'. Both smoking and sun exposure were recognised universally as risk factors but knowledge of other risk factors was

patchy. The role of alcohol and exercise in particular were not recognised. Other, what are often called mythic factors, were cited including environmental and social factors. Most participants were generally cautious about making aetiological links between many of these factors. There was, particularly amongst the female participants, a tendency to be nostalgic for a time when life was more 'natural'. Clearly behavioural factors are often at the heart of explanatory models, though fatalistic ideas of luck and randomness are introduced when no other cause can be located. Allied to this is the idea of a dormant gene, triggered by a series of factors. Essentially this represents a quasi-scientific interpretation of luck. The findings show that underlying moral judgements are often implicit in conversations about health.

What does this data tell us about the utility of lay epidemiology and cancer? Chapter 10 focuses on how the data generated in interviews relates to the lay epidemiology model.

10. Lay Epidemiology and cancer

10.1 Introduction: lay epidemiology revisited

This chapter concentrates solely on lay epidemiology. Chapters 8 and 9 looked first at the participants' experience of cancer, before going on to consider what meaning and understanding of cancer they had derived from their experience. What these chapters demonstrate is that although personal experiences of cancer varied, there are a relatively small number of common, typical narratives that characterise the cancer experience. The original concept of lay epidemiology referred to a system that drew on information from a variety of sources in order to formulate ideas about CHD risk:

“ refers to a scheme in which individuals interpret health risks through the routine observation and discussion of cases of illness and death in personal networks and in the public area, as well as formal and informal evidence arising from other sources, such as television and magazines” (Frankel, Davison & Davey-Smith 1991:428)

The mechanism central to the model is 'candidacy', which allows the identification of individuals thought to typify the most or least likely candidates for heart disease. Key, is that individuals recognise that candidacy is fallible. Fallibility is operationalised through the evocation of anomalous deaths and unwarranted survivors. Irrespective of its flaws, candidacy provides the basis for an estimation of risk, both in oneself and others.

This final chapter of findings presents the data generated in interviews, using the concepts embedded within lay epidemiology as an analytic framework. The key areas of explanatory models, risk and candidacy will be reflected on.

10.2 Explanatory models: the need for explanation

It is accepted that people need to better understand events and often construct models to explain the cause of illness (Kleinman 1980). The participants in this study were no different, and while they may not reach definitive answers, those with close family members affected by cancer describe a process where they searched for explanations or meanings. A criticism of qualitative work and of content analysis is that it decontextualises narratives and fails to account for the

potential influence of biographical circumstances on findings (Wilkinson 2000). 'Proximity' attempts to address this potential shortcoming. As already described, proximity refers to the level of closeness to people with cancer. Of course there is a need to be cautious because perceived 'closeness' varies within families. For example, Janet described the shock of a paternal aunt dying of oral cancer and how the event had forced her to re-evaluate her own behaviour. Meanwhile Lorna reported that she felt lucky that cancer did not appear in her family but went on to recount details of the cancer deaths of a paternal aunt and uncle. Allowing for such caveats, the findings show that those with a closer proximity to cancer discussed the general subject in a more thoughtful way; they tended to be more proactive in seeking information and were more dogged in trying to establish causes. Blaxter (1982) advised that any discussion of disease typically results in a discussion of causality and the subject turned to causes very quickly in most interviews. Yet, proximity can refer not only to familial 'closeness' but also temporal closeness. Grace, whose husband had died of colorectal cancer six years before the interview, seemed to be less concerned with understanding than other participants in similar but more recent positions. If an event is relatively fresh it is possible that participants remember more detail. Instead, Grace conveyed a general feeling rather than precise detail. Indeed, Grace's husband was first diagnosed ten years before his death, so her experience could reasonably be termed historical.

Previous chapters demonstrated that participants used narratives to express their views and to provide evidence for their positions. This method of discussing cases anecdotally was also found by Scanlon et al (2006) in their focus group study that considered the experience of cancer amongst the Irish community in the UK. Embedded in such narrative accounts within this study were questions and ponderings about why the disruptive event, namely cancer, had occurred. Understandably, this need was felt most keenly among those with a closer proximity to cancer. Peter suggested that this goes beyond cancer and may be applied to other illness experiences:

I think people don't think a great deal about cancer if there is no one they know, or in their family or their good friend who has had it or has lost someone from it or is suffering from it. It's really when someone they know takes it that they really start to think about it

and that's true of a whole lot of things, not just cancer (Peter 67 Deprived)

What Peter is describing here, only thinking about an illness when confronted with it, is not uncommon. Salant & Gehlert (2008) reported that this was the reason given by their focus group participants for not considering their risk of breast cancer. More generally this is a notion which fits in with health being synonymous with an absence of disease and need only be tackled in response to an illness event (Blaxter 1990).

Cancer, as illustrated in previous chapters, continues to represent fear and unpredictability. Making better sense of the event might help to deal with traumatic episodes. The following extract captures Clare's search for meaning about mother's case and her need to gather relevant information to bolster her explanatory model. It also shows that Clare, though not "actually really researchingit", does admit that she will now read articles she may previously have thought irrelevant to her:

My mum's breast cancer, I guess that was more of a surprise, a big surprise because she was a very healthy person, very fit active healthy, good diet. I mean, all the boxes you think you should ticking so that was a big shock. But I suppose in retrospect em although my sister and I have looked at it and thought there was a lot of emotional issues and wonder whether there wasn't a psychological element going on there. And I suppose em, you know, in terms of just in a more general picture I'm quite, I guess I'm quite open about it because I think well there are some quite clear physical things that are going to make the risk factor, the risk of getting it greater. There's also the genetic line and there's also I think a psychological or emotional element involved in it as well. And I don't know whether I've come to that view because I've experienced more of I, em cause my dad's mother, my grandmother, also died of cancer but she was a good age it wasn't sort of ... Em (sigh) or and I suppose I have probably, I haven't like actually really researched it despite what I have experienced but I guess I've read articles, you know, if I've come across stuff in newspapers and things, I mean now I would probably read it. So I guess maybe that's why I have more a mixed view about some of the causes. (Clare 42 Affluent)

10.3 Developing a personal evidence base

The lay epidemiology scheme described by Davison is mirrored in the data generated in this study. A similarly complex model of information gathering and

analysis was apparent and within interviews participants' talk often flitted between descriptions of close personal experiences, examples from discussions held within wider social networks, established health education messages, and information gleaned from the mass media. The data presented show an unquestionable level of sophistication in their explanatory models.

The above extract from Clare encapsulates the model in action. Her mother's cancer event challenges her previous knowledge about cancer. She is required to consider alternative explanations, and does so in light of information from legitimate sources. Her explanatory model is adapted to accommodate new experience. It is no surprise that this formula has a role in the search for explanation. It seems logical that individuals will consider their most recent experience, compare it with the data that they already hold both from past experience and wider information sources, and reshape their belief model accordingly. Individuals construct their own personal 'evidence base' by synthesising what they 'know'. Such a base is not static; it is adjusted to incorporate new data, both contradictory and confirming. In this respect it is comparable to traditional scientific approaches to dealing with evidence.

10.3.1 Gathering evidence

Evidence took many forms. As detailed in previous chapters, evidence was not confined to close experience, nor did participants rely solely on official sources. Instead it was a hybrid. Personal experience, instances from social networks and the community, cases reported in the media, information from professionals, research (as presented by the media) and health education have all been shown to have a role in informing the model. Not all sources were given equal weight:

You read what you read in the papers and you usually take what you read in the papers with a pinch of salt, but it does put the thought there like the mobile phone masts and things. But it's not, I don't drive around and think 'Oh look at all this pollution that's causing cancer.' I don't drive around or, 'there's a telephone mast I bet folk around there have got'. (Emily 37, Affluent)

The relative weight of importance given to each source depends on proximity and individual experience, which is subject to change. Participants reported frequently that their views had changed. Often a single disconfirming event was

all that was required to reshape their explanatory model. As already detailed, Clare provides an account of how her mother's breast cancer event had changed her view because she could not 'tick' any of the expected 'boxes'. Similarly, Emily discussed her uncle's unpredictable throat cancer and reported that this had forced her to look beyond lifestyle factors when judging causality. More specifically Jessie tells of her re-evaluation of the protective benefits of breast-feeding:

I always thought that if you breast fed you had less chance of developing breast cancer and .my friend in Edinburgh, she breast fed and she developed breast cancer, so my theory is sort of out the door in that respect. (Jessie 68, Affluent)

What all three of these participants highlight is that information need not be received from a close family event to force a re-evaluation. Although for Clare her mother's cancer had prompted the search for alternative explanations and cast doubt on her received view. Emily however, talked about her uncle, who she also described as being in her wider family. This was partly because he did not live locally and more importantly because he was not actually 'related' to her. He was her uncle by marriage. Finally, Jessie is describing information from her social network. These are three distinct levels of relationship at varying distances but all experiences had significantly altered explanatory models.

10.3.2 Expert sources of information: the certainty of science

A coronary candidate is recognised both by the lay epidemiologist, and the 'expert' alike. The term lay epidemiologist referred to the means employed, like the gathering and ordering of evidence, by ordinary people to arrive at a risk estimate for CHD. Among the South Wales cohort there was a clear acceptance and understanding of the current 'expert' risk factors for CHD. Ultimately Davison's model of lay epidemiology for coronary candidacy is reliant on such an understanding amongst the lay public. For Davison and colleagues the challenge posed by lay epidemiology was in the realm of health promotion, and in particular the 'certainties' it promoted. The lay epidemiologist is adept at making risk assessments. Moreover, by acknowledging the failure inherent in the candidacy model they arrive at a position, according to Davison, that makes it easier to prevaricate about behaviour messages. What if the lay view is more at

odds with the scientific view? What if the epidemiology of cancer is less well understood? Some participants were slightly sceptical about the knowledge of science in the area of cancer. The unpredictable and random nature of cancer meant that many participants felt that science could not explain cancer and that ‘they’, the doctors, were sometimes no surer:

I think again, I think, maybe I’m completely wrong here, but what I can glean from the media and the newspapers is that maybe they are getting closer as regards some specific cancers but they are totally in the dark about others (Lisa 45, Affluent)

I think bit by bit you can find associations and manage types or whatever maybe find preventative like gene therapy that kind of thing but I’m not quite sure whether science will ever be able to take away the risk completely (Emily 37, Affluent)

I think there’s a lot of things that science can’t prove or disprove and some things aren’t logical. I mean why does homeopathy and acupuncture and things like that work for some people and not others? Is it faith? I’m not a greatly religious person but you can’t explain some of the things that happen (Peter, 67 Deprived)

Colin often expressed his faith in science and in particular his scepticism about the environmental causes of cancer. Ultimately though Colin questioned the certainty of science:

I mean, point to the electricity pylon that’s what I was going to say. The electricity pylon stuff and mobile phones and mobile phone masts and all that. As I understand it there is as yet no hard scientific evidence which says either mobile phone use or mobile phone masts do generate cancer hotspots..... but my understanding is that em medical science still does not properly understand where cancer comes from eh what causes it, you know, what the physical triggers are and so on although, you know. We know that certain circumstances will make its instance more likely (Colin 61, Affluent)

Although this represented a contradiction, it does hint at the cultural position of cancer in society. Cancer is represented by uncertainty both at an individual and at a population level. Many possible causes, some controversial, are trailed in the mass media and although often controversies are easily dismissed, the lack of certainty looms large.

10.4 Comparisons with Coronary Heart Disease

As Davison's original theory of lay epidemiology emerged from an ethnographic study with Coronary Heart Disease (CHD) as its focus, it was judged appropriate to ask participants in this study to compare CHD and cancer. There was universal agreement within this study group that CHD was 'easier' to explain than cancer. Participants seemed surer of CHD causality. Like Davison's cohort, CHD was perceived to be caused by behaviours, primarily diet, but a strong family link was also apparent. The following extracts are typical of those found throughout interviews:

I think heart disease, if you don't exercise and eat lots of fatty food and if there is a predisposition of heart disease in your family then I would say possibly the chances are you'll get that yes, uh huh. (Elsie 62 Affluent)

Heart disease again, heart attacks run in some families and not in others. Diet is a big contributory factor and lack of exercise, fatty foods, eh, eating the wrong types of fatty foods em, I (pause) don't know if I can explain it. Cancer I think is much more complicated and there's more varieties, versions of it. (Peter 67, Deprived)

Whereas in heart disease, again as I as a total lay person, as I understand it then, you know, the physical causes of heart disease are quite clearly understandable and the physical actions or inactions that lead up to these things being in place are understandable and understood and so in that sense it's yeah it's better understood and so on. I mean the actual genus of cancer may not be understood but the circumstances in which it's likely to arise pretty well understood I think. (Colin 61, Affluent)

There was also a tendency to believe that heart disease was easier to control or protect against:

I'd be more likely if you asked me if diet and exercise were likely to influence your chances of dying from heart disease, I'd be more likely to say. Now again, I'm totally unscientific, I don't have any medical knowledge at all but I would say that its easier to affect your life chances from the point of view of heart disease than of cancer because to me it just seems totally random, you know children that get leukaemia and things like that, they don't all live beside a chemical plant so, I don't know, I honestly don't know. (Lisa 45, Affluent)

These extracts illustrate participants' confidence in a better understanding of CHD. The perception is that CHD is relatively simple and the mechanisms that result in CHD are easily explained. The same is not true of cancer. This resonates with Balshem's (1991) findings, where participants saw heart disease as '*a matter of mechanics gone wrong*' (Balshem 1991:158) while participants response to questions about cancer '*touched on universal mysteries*' (Balshem 1991:158). Cancer's relative complexity was also displayed in the pictorial images offered by participants in Weiss' study (1997). Davison suggested that lay knowledge and understanding of CHD was good. Typically studies suggest that lay knowledge and understanding of cancer is poor (Randhawa & Owens 2004; Scanlon et al 2006) both in terms of cause and risk, and when unpicked many persistent misconceptions are uncovered (Dein 2004).

Essentially this provides a significant challenge for those tasked with spreading messages about cancer prevention. Davison and colleagues commented on the width of the candidacy concept. Any factors, even those at opposite ends of a spectrum, for example no physical exercise and over-exercise, could be used retrospectively as an explanation for a cardiac event. With the exceptions of smoking and sun exposure, the risk factors associated with cancers, in comparison with CHD, are relatively poorly understood. Thus explanations based on misconceptions like stress or triggers become more plausible.

10.5 Assessing risk

The estimation of risk is at the crux of the lay epidemiology model and this will be returned to repeatedly in the remainder of this chapter. Davison and colleagues concluded that while it was relatively straightforward to retrospectively decide causes in relation to a CHD event, deciding the future probability of an event is more challenging. Davison and colleagues thought this applied equally to oneself and others. The entire scheme rests on individuals basing judgements about risk on evidence and consequently forming a reasoned opinion about relative risk. At the centre of this risk assessment is the creation of an ideal type or what Davison referred to as 'candidacy'. Comparing oneself and others to the candidate profile allows future risk assessments to be made. Before going on to explore candidacy, participants assessment of risk will be looked at in more detail.

10.5.1 Population Incidence

Participants were initially asked about their awareness of the population risk of cancer. At least half of the participants believed the risk to be one in three, in line with current health information. The interpretation of risk among some participants was noteworthy. Angus was one of four siblings. His elder brother had already died of pancreatic cancer and another brother had recently been diagnosed with a rare form of colorectal cancer. Both he and his youngest brother remained healthy. Angus understood the statistic quite literally:

Well the (sigh) the one in three, right, I reckon from my generation, of my family, according to one in three, I'm safe now. But according to my family, my wife, my daughters, one of the four of us in that group should have cancer of some type. But that's what should, if you go by the stats (Angus, 57, Affluent)

In previous studies of cancer awareness the link between age and cancer is poorly recognised for certain cancer sites (Paul et al 1999; Keighley et al 2004). Some participants in this study did make such associations. Here, Kathleen makes a distinction between 'lifetime' risk and absolute risk:

Well according to billboards and things like that, they say three in five. Bowel cancer I think they say one in seven or one in eight or sometimes as low as one in six, depending on, you know if you have cancer already in your family. So, its not surprising if you stop and think about that. I do know quite a lot of people over the last two or three years who have had cancer and also your risk gets higher as you get older and more of us are living, I don't feel as if I've lived my life yet, but more of us are living longer, so we are going to have people being diagnosed I suppose, you know in the later, I mean your risk for breast cancer is much greater once you're over 50, I think it is (Kathleen 68, Affluent).

Others studies (Humpel and Jones 2004; McMenamin et al 2005; Linsell et al 2008) have found that participants both under-estimated and overestimated their risk and both positions were found among participants in this study. Peter, for example:

I would have thought you've got a 50/50 chance of having some form of cancer or not. (Peter 67, Deprived)

The previous chapter revealed that most participants felt that cancer was common and was becoming more so. Nevertheless, many were surprised that that overall population risk was as high as one in three. Some perceived this to be an extremely high level of risk. This was particularly true in the deprived community.

10.5.2 Personal Risk

Assessment of personal risk had three distinct, but often overlapping, components. Participants thought about the risks associated with their behaviour and family history but also their estimation of risk in light of the perceived commonality of cancer.

Participants were not asked directly about their behaviour but often the discussion strayed into that area. Typically the conversation about behaviour centred on diet and exercise. Health education messages about consumption of ample fruit and vegetables, and drinking within sensible limits, were well established. Most participants reported that they were 'good' most of the time, but there was a tendency to think about behaviours in terms of 'moderation', as Backett (1992a) also found in her Edinburgh cohort. This was strongly bound with the notion that denying oneself 'the odd treat' could ultimately prove detrimental to one's health. The key to health was a balance. In the following extract Peter echoes what Davison found in Wales, that being too fit could be equally damaging:

There's nothing wrong, I think, in having the odd unhealthy meal and who's to say its unhealthy but not if you were eating it breakfast lunch and dinner, seven nights a week. Chinese takeaways or Indian takeaways then you're asking for trouble with weight, with health and other things and I think the secret is having a balanced diet but no matter what you do you could still. I mean look at the number of people that go out jogging and drop dead with heart attacks, yet to all intents and purposes they are very fit. Fitness and health are not necessarily the same thing. People can be healthy and unfit and people can be fit and unhealthy (Peter 67, Deprived)

Again Kathleen and Jessie both emphasise the value of moderation:

I think it should always be said that, well they don't want you to sit in your house well, they want you to exercise for everything don't

they? But you don't want to sit in your house and be frightened to eat this, that and the next thing. I really think its all things in moderation. I had an iced-bun last night and I will have another iced-bun - because it was a pack of two (laughs) but I do eh, use Bertoli and I use semi-skimmed milk. In fact, I buy organic. (Kathleen 68, Affluent)

Oh, I'm very careful with my diet, we do have a Chinese carry-out, don't think that we're goody goody every night, we do have a Chinese carry out and we go out for a meal every now and again but at home its good basic food and we've got biscuits in the house (whispers) but we try not to. If someone gives me chocolates, I eat them (laughs) because its bad manners not to but I shouldn't really. Och, a little bit of what you fancy, everything in moderation. I just say, everything in moderation and if I get it, I get it but if I don't I've worked hard not to get it. (Jessie 68, Affluent)

Many of the participants reported that they engaged in healthy behaviour because that is what they enjoyed. The avoidance of cancer or other diseases was not the motivation for their habits. In the following extract Colin highlights what he sees as the basic rules, before going on to give his reasons for following the rules:

And, you know, eat a sensible diet and take sensible exercise and breathe some decent air once in a while, don't sit in your car all the time the normal basic rules and em your likelihood of having problems is reduced but that's about as far as it goes isn't it?

Later he adds

But no, I mean I didn't start off being self conscious about my health, I started out by being self conscious about doing things that I enjoy doing and just by and large they just happened to be healthy things. (Colin 61, Affluent)

A few participants were less positive about their risks and were aware that their current lifestyle was unhealthy and may increase their risk of cancer:

Well, certainly higher (risk) than my wife's and higher than my brother's because of the amount of alcohol, and food, I mean I don't eat enough vegetables - I take a vitamin tablet now and again. I will go over the 20 units of alcohol, I'm not saying I'm proud of that but I probably have 35 or 40 a week. (Andrew 57, Affluent)

I mean likes of just noo I'm overweight the noo I'm about four, five stone overweight. I'm no eating right and I'm maybe drinking a wee

bit mair than I usually drink. If I go on a diet and start eh eating properly and daen a wee bit mair running, I could easily go oot running eh and that will kind of help me against it. (Gary 37, Affluent)

Smoking was seen as a major risk factor and only a handful of those interviewed smoked. Those that did smoke were clearly aware of the damaging effects of smoking. Colin, who outlined the basic rules above described his behaviour, in terms of smoking, as “stupid” but reported that he had “cut down” and had previously attempted to give up. He was keen to bring attention to the healthy behaviours he did engage in and his belief that he was “healthier” than most people, thus offsetting the overall risk of smoking. Josephine, who also smoked, was instead keen to stress that other factors as well as smoking were important:

Don’t get me wrang, I mean I dae say, aye smoking’s a contributory factor but it’s no the be all and end all. (Josephine 61, Deprived)

All of the smokers excused their continued smoking by discussing additional health problems. Careful monitoring of cholesterol, for example, was seen as a more immediate challenge than the threat posed by smoking. Not surprisingly smoking was always negative. Some participants talked about family members who had smoked and were eager to portray their relatives in a manner that removed smokers’ culpability. Murray was clear that, as he put it, “avoiding carcinogens” was the key to avoiding cancer. Tobacco was foremost among those carcinogens. Murray went on to report that both of his parents had smoked but placed their behaviour in its historical context, which he felt was important:

Well my parents would have started smoking I suppose as most people do in their late or mid teens which would put it back to the First World War and the risks I think were not generally known, not even amongst the scientific community at that time. So, you know, I don’t think they were foolish (Murray 83, Affluent)

Murray was fairly vehement in his anti-smoking stance yet towards the close of the interview he returns to his mother’s death:

Well interestingly enough when my mother, although I don’t know why a post mortem was asked for, I didn’t ask for it, it must have been my brother but she had a tumour on one lung but on the other hand it was the kind of tumour that grows very, very slowly and it

*probably wouldn't have killed her and she lived to be 92 anyway.
(Murray 83, Affluent)*

Here Murray reveals that his mother did indeed have lung cancer, but he is keen to stress that it remained undiscovered and would not have killed her. Murray was rare in that he began the interview by stating that he knew no one 'close' with cancer and that he had little to offer, though evidently his mother had lung cancer. That she had not died of lung cancer perhaps negated the need for him to incorporate this into his explanatory model.

Risks were not confined to behavioural choices. As per participants' explanatory model, a series of factors were taken into account when estimating risk. Most prominent was a family history. Those with a 'family history' of cancer did not necessarily always believe that this automatically elevated their risk. In the following extract Clare discusses her risk:

No, I don't I mean I suppose it's one of those situations where I sort of think, well if you put me in the sort of risk category boxes in terms of diet, lifestyle, stress, drinking, any of those kinds of things. Well it's no to all of those, em family history well yes there has been cancers in my family but all of them have been different.

Later she adds:

(Sigh) Well I think it means that there's no way you could sort of say "Well it's likely I would have breast cancer or bladder cancer or cancer of the uterus" just because that's turned up in the family. I think it's quite likely I might have cancer just because it's quite likely I might have cancer, I mean I think that and I don't think it's not going to happen because I can tick all these boxes in the lifestyle thing. (Clare 42, Affluent)

What was important for Clare was that the experience was of 'different' cancers, and it might be inferred that she might feel differently if there had been multiple occurrences of the same cancer within her family. Yet the occurrence of cancer in her family, despite healthy lifestyles has led her to re-evaluate her risk. In light of her experience, she now thinks it likely that she might get cancer because lifestyle choice provides no guarantee and because cancer is common. Angus, who had also experienced more than one cancer in his immediate family, initially voiced some concern at the possible genetic link but later dismissed it:

I don't know I actually phoned my GP and said "You know, I've got no signs, nothing's happening, I don't feel any different. Well that's two brothers died of cancer now and my niece has got cancer, now is there a family link? Should I be looking at anything should I take a pro-active approach or just wait and see?" And she came back and said "Well I'll refer you to the Genetics Unit" or something.

He added

I'm not bothered it's eh I'm quite sort of I don't know optimistic, I don't know what you would call it, optimistic, I'm optimistic that it'll never happen to me. And that's the mental attitude I'm taking, it won't happen to me because I'm doing all the right things and if it does happen to me I'll fight it and I'll win. (Angus 54, Affluent)

Angus believed that his 'good' behaviour will supplant any possible familial links. Although Clare and Angus adopt different positions they do so in the context of more than one case of cancer in their immediate family. Both have considered the possibility of genetic links and both have dismissed them, though they arrive at their positions for different reasons. They also arrive at different conclusion. Other participants, who believed themselves to be in 'cancer families', thought that their risk was elevated. Kathleen thought of herself as being in a cancer family and although the majority of those cancer events were not amongst her immediate relatives, she regarded them as so. Her family status effectively cancelled out her 'good' behaviours:

Kathleen: So, I think my risk might be slightly higher, I would have said my risk was higher than my friend who is going into hospital today (for colorectal cancer surgery)

I: You would have said your risk was higher?

Kathleen: Yes, well the number of people in my family, in the immediate sides of my family except that I have probably not drunk or been as overweight, you know, as her, but looking at in anything you might get through your family line I would have said that my risk was higher than hers (Kathleen 68, Affluent)

The majority of cancer within Kathleen's family had been among her aunts and uncles. Pauline also had aunts and uncles who had died of cancer but she did not regard this as her "family". This re-emphasises the importance of perceived proximity when considering the impact of family experience:

I suppose I've got the same risk as everybody else but it's no something I worry about maybe because it's never been in the family. (Pauline, 57 Deprived)

Assessing one's own risk in the comparison to someone else was more usual than thinking about oneself in the context of absolute risk. Moreover, because risk was often over or underestimated when compared to the actual population incidence, personal estimates were vague and ill-defined. Yet, it was unusual for participants to report that they felt that they were at an especially high risk of cancer. It was more usual for participants to state that their risk was low. Murray, perceived his risk to be low and attributed this directly to his behaviour. The following extract is especially interesting because as the earlier section showed Murray's mother had lung cancer. Though clearly because she did not die of lung cancer, this has not entered into his explanatory model:

Very low. Because nobody in my immediate family has or has had cancer and I think there is a genetic element in there somewhere. Also I reduce my risks of not getting cancer by not being a smoker, never have smoked (Murray 83, Affluent)

Participants were not always rational or logical in their reasoning around personal risk assessments. Elsie whose mother and husband both experienced cancer talked about her strategy for avoiding cancer. Here, she hints at the importance of attitude as well as behaviour:

I mean my mother was eighty-five when she got it, she only lived another two years. But I just think to myself "No that's not for me" I don't know, I just say "No I'm just going to lead my life and go out and do my walking and go to my wee keep-fit class and go and meet my friends and I'm not going to get it". Maybe that's stupidity on my point or naivety. (Elsie 62, Affluent)

10.5.3 Risk of other individuals

As has been shown in Chapter 9, there was not universal acceptance, with the obvious exceptions of smoking and sun exposure, of links between behavioural or environmental factors and cancer. Rather, there was a universally recognised model of 'healthy'. Many of the cancer sufferers known to the participants fitted that 'healthy' typology, which ultimately made the estimation of risk in others difficult. There was the easy identification of those who should, according to

their behaviour, get cancer. Clare sums up the difficulties associated with estimating risk in others:

I think, you know, there are things like that, you know, big killers like heart attack and that seems to be, that can seem to be quite random as well but then you can look at other people and say oh yeah but you've got all the factors that's a high likelihood. So I think I'm seeing a lot of diseases as yeah there's one's that people who tick a lot of the boxes and have the risk factors and another set of people who don't really and yet they can still be affected in some instances (Clare 42 Affluent)

As Clare states the relationship between known risk factors and disease occurrence was often not borne out in experience. As Julia notes when talking about a neighbour who was diagnosed with cancer and expresses her surprise at the diagnosis because she had always looked “healthy”:

Because, she was always so healthy looking and working hard and everything else and that was their retriial. They had sold up and moved to Millport to retire, even although she's a fair number of years younger than me and she took cancer (Julia 65, Deprived)

As previously noted the model of lay epidemiology provides a vehicle for an estimation of risk. Central to that estimation was the identification of a candidate who is thought most likely to suffer CHD. The following section on candidacy will explore the estimation of risk further.

10.6 Candidacy

Davison regarded candidacy as a critical ‘cultural mechanism’. Coronary candidacy broadly captured the public’s view of the kind of people who are likely to experience or escape heart disease. Participants in this study rarely talked about cancer in such terms. Although it was plain that there were a series of factors that contribute to candidacy for cancer they were generally resistant to the idea that there was a ‘type of person’ who got cancer. In thinking this through, Gary made a direct comparison between CHD and cancer:

You're talking about diet and lack of exercise and everything. A lot of people are stressed and say “They're gonnae kill themselves, they're gonnae have a heart attack” but you don't hear people say “He's eventually gonnae get cancer.” (Gary 37, Deprived)

Gary's statement is easily recognisable and encapsulates the universal language used when talking about disease. Within it there is recognition that we talk about heart disease and cancer in different ways and neatly illustrates many of the points made by those who consider the cultural position of disease (Sontag 1978; Lupton 1994; Weiss 1997).

This crucial difference between cancer and heart disease is also highlighted by Lisa:

Do you know, its funny that, its not something I have ever thought but just doing a kind of quick inventory of all the people I've known who have had cancer, you know I can't think of one single person, I would say, well yeah that was coming, no I can't. No. I've known, as I say, I've known people who have maybe had a heart attack and died and I've thought " Oh God yeah, I mean he was 48, two stone over weight and smoked 60 a day and you know was in an extremely stressful job as a lawyer" and you know when he dropped dead in the office you thought hm, yeah, no surprise but not as regards cancer. (Lisa45, Affluent)

Lisa, in her description of the CHD sufferer, includes all the characteristics included in the coronary candidacy model described by Davison. Features of CHD candidacy are common in everyday illness narratives and Lisa demonstrates this by making direct comparisons with cancer. As both Gary and Lisa testify, the easy evocations of CHD candidacy tend not to apply to cancer, either universally or by participants in this study. Though Davison does allude to the problematic nature of the term candidate, in so far as one is essentially being asked to nominate oneself (or someone else) for a serious disease, coronary candidacy, especially in others is well-established.

The reluctance of participants in this study to 'single' people out and ascribe candidacy points to the status of cancer in our society. The dreaded nature of cancer is well documented. Cancer was once stigmatised primarily because of a widespread lack of understanding of cause and almost certain death (Sontag 1978, Patterson 1987). Although stigma remains it has shifted focus slightly because of the emphasis on individual responsibility in disease prevention and avoidance. Nowhere is this more evident than with smoking. The attitude towards smokers displayed by some of the participants in this study resonates with other studies looking at smoking and personal responsibility (Muzzin et al

1994, Chapple, Ziebland & McPherson 2004). Yet, there continues to be a significant segment in the cancer puzzle unaccounted for which furthers misunderstanding and fear (Comaroff & Maguire 1982). The uncertainty and fear that shrouds cancer was sufficient to discourage some participants from making candidacy judgements:

I don't think you kind of single out so many people and say "Right I don't think she'll get cancer because" or "I think they two will have cancer" I widnae kind of single people out to say I think they would get it. (Karen 25, Deprived)

Karen describes what Davison referred to as prospective candidacy. As previously noted, Davison conceded that retrospective candidacy, where candidacy is used as an account for past events, had more salience. The same was true for participants in this study. It could be argued that using retrospective candidacy, as a mechanism to explain past illness events, seems obvious. It appears logical to deliberate known risk behaviour and judge whether they fitted the relevant disease candidacy type. So cancer candidacy was accepted for smokers, sun worshippers, those with unhealthy lifestyles and those exposed to environmental hazards. In the following extract Lisa discusses the candidacy profile of an elderly aunt who had breast cancer. Eventually, Lisa concludes that breast cancer was not responsible for her aunt's death but given her age and behaviour, judged her to be a likely candidate for breast cancer.

My own aunt had actually died, she was diagnosed with breast cancer but um, again it sounds a bit odd to say but she was in her mid 80s and she smoked very heavily all her life so she was kinda dying anyway, you know she had lots of other illnesses and she had been in and out of hospital and eventually someone said "Oh by the way, she's got breast cancer as well". So it was like, oh God, not that as well but em, in a sense, you know somebody said to me at the time, you know she's not gonna die of it at that age, she'll die of other things because it's hormone driven, which again, I didn't know. (Lisa 45, Affluent)

Similarly, Kathleen discusses her close friend recently diagnosed with colorectal cancer. Elsewhere in her interview Kathleen tells that she had sought information about colorectal cancer for her friend and in the following extract describes risk factors that coincide with her friend's behaviour:

She's overweight, she has always been a bit overweight, she drank, I think always quite a lot, and em but had stopped smoking maybe about 30 years ago but had done things maybe like the Atkins diets sometimes and all that fatty stuff you know, which I don't think really is a help to anybody. (Kathleen, 68, Affluent)

What is interesting about Kathleen's description of her friend's candidacy for colorectal cancer is that when previously asked about her own risk, Kathleen had stated that she had thought her risk higher than her friend's. She based this on her own family history. Kathleen had not previously recognised her friend as a candidate. But in the event of cancer and with the presence of risk factors, Kathleen had retrospectively applied candidacy.

Betty also talks about a friend's behaviour. Here Betty is retrospectively applying candidacy, which is framed by newly available information. In this context prospective candidacy would not have been possible because, as Betty states, the links between sun-exposure and skin cancer were not widely known. Betty is however able to make a judgement of candidacy in light of new evidence.

Well I thought the girl with skin cancer eh she never, ever used any lotions but I'm going back, she's dead now over twenty years, right ... And she was in her forties as I say she was about forty-six and we didnae know about creams, you know, and she was a sun worshipper. She went to, she had a daughter was married to a boy in Tenerife, I couldnae remember the place, Tenerife, and they went there for six months at a time. Eh, so as I say, I felt she could have done something, she could have stayed out of the sun. (Betty 61, Deprived)

Only once did a participant express surprise at someone having escaped cancer. Josephine's husband had died of CHD but she had been sure that he would develop colorectal cancer:

I always thought he would take it, you know, wae the history of his mother and faither having it and him being overweight. (Josephine 61, Deprived)

Candidacy judgements are not confined to those whose behaviours one has knowledge of. In the following extract Grace discusses the case of John Wayne, who also died of cancer. Though Grace is unlikely to be aware of his risky

behaviours, she made a link with widely known and supposed environmental risks:

John Wayne died of cancer of the throat and em he was down in Nevada or something where they'd been testing the nuclear, he was doing a film down there and quite a few of the people who were in the desert filming spaghetti westerns and things like that died of cancer where they were doing the nuclear tests. (Grace 63, Affluent)

Although judgements of candidacy were not always obvious or transparent, smokers were almost universal in being seen as cancer candidates. Before going on to explore candidacy, it is worth focusing on the importance of smoking and its significance for candidacy.

10.6.1 Smoking – a special risk factor

While certain behaviours, like the all-encompassing unhealthy lifestyle, were linked with cancer, smoking was afforded a special status. When recounting a cancer narrative, the sufferer's smoking status was always disclosed at the outset. Davison noted the importance of weight or physical build for CHD candidacy and smoking assumed a similar role for cancer. Although it is useful to draw parallels between weight for CHD and smoking for cancer, the two differ in an important way. Physical stature or weight presents an immediate visual predictor of candidacy. In the current climate, particularly where smoking is prohibited in many social settings, an individual's smoking status is not so widely known. Therefore, it was not uncommon for participants to seek confirmatory details of a sufferer's smoking status from a spouse or partner not participating in the interview. Thus smoking, or non-smoking, was almost always at the centre of the explanatory model. If the individual was judged to be a 'heavy' smoker, the search for additional explanatory variables ceased. Though most participants did not articulate connections between smoking and all cancers, others were clear of the importance of smoking in any model of cancer candidacy:

No, I don't think there's a type (to get cancer), if one excludes the 60-a-day smoker type, I don't think there's a type. (Murray 83, Deprived)

As has already been noted, smokers have been found to experience stigma in response to a lung cancer diagnosis (Chapple, Ziebland & McPherson 2004). The

stigma attached to smokers and the consequential judgement on personal culpability was also seen in this study. Some participants were eager to downplay the importance of smoking in their otherwise healthy relatives' cancer diagnosis or assumed that stopping smoking prior to diagnosis removed any potentially harmful effects. The following extract details Jessie's response when asked to comment on retrospective candidacy:

I: Is there anyone that you have known who has had cancer that you might have thought, well, yes I can see why they would get cancer?

Jessie: No, not amongst my friends or relatives. My mother maybe yes because of her smoking but I sort of put it aside because she was always a very healthy lady (Jessie 68, Affluent)

Earlier in the interview Jessie had talked about smokers in the context of her own risk:

So I eh, eat fruit and vegetables and wholemeal bread because I want to try and avoid it but if I can't, I can't and that's it. You know. I don't know about normal people, I mean you go out and you see people smoking away like (laughs) chimneys and if you don't die of ... I mean I attend [hospital] and if they don't die of lung cancer they'll die of pneumonia because they are out there in the cold in their dressing gowns smoking (Jessie 68, Affluent)

Jessie makes no attempt to hide her disapproval of smoking. By highlighting smoking outside the hospital she hints at issues of personal culpability and displays the significance of moral judgements when arriving at explanatory models of disease. Elsie was similarly keen to absolve her husband of culpability, as the following extract shows:

I'm inclined to have wee thinks to make up my mind, I might be entirely wrong. He was a Commercial Artist and away back, well he used to take his paintbrush into his mouth and suck it to get a nice point to do the lettering and I thought, I think I'd read something or I'd seen it on the television there was a factory I think somewhere about Dundee, I think it was clocks they made, and the faces to make the face of the clock or the numbers luminous the women there who painted the dials had radioactive paint they used and quite a lot of these women apparently died of cancer. And I said to him, it wasn't till after, it was quite a long time after, I said "Do you know what I think?" and he said "I never thought about that" and he said "Right enough the water was mucky and you just put your paintbrush in and

you went like this and you got the paint". So maybe that is quite entirely wrong.

I: Can you think of any other cause?

Elsie: No. Well, he smoked.

I: Right.

Elsie: He doesn't smoke now and he'd actually stopped the year before the cancer was detected, he did smoke so caused by smoking yes, smoking, uh huh, yes, uh huh.

Elsie presents a narrative that she is comfortable with and is acceptable to her. She had established that her husband's environmental exposure at work had been important in the aetiology of his cancer, albeit that it stemmed from his own individual way of working. She had decided to dismiss smoking but introduced it nevertheless. Smoking could be ignored because he stopped prior to his diagnosis, though arguably he had retired many years before giving up smoking.

10.6.2 Explanatory hierarchy

If smoking was not implicated as a cause, participants searched for additional variables that could reasonably be entered into the explanatory model. Much like Davison originally found, participants in this study question a series of possible explanatory factors that are entered into a model to provide a profile of the individual. This may then explain why they got cancer when they did, in essence what set them apart. Once the smoking status of the sufferer is established, the search moves to other plausible risk factors. Rather than specific behaviours, with the exception of sun-exposure and skin cancer, it is a more holistic enquiry about general health. This included a health history and family connections. The current weight, diet and alcohol consumption of the individual also acted as possible reasons for the occurrence of cancer. The relative importance of each element for the explanatory model was individually tailored. This is a striking difference with candidacy for CHD. CHD is a single disease with a limited range of risk factors, which are well established among the lay public. Cancer is more complex, so while candidacy for lung cancer, for

instance, may be well-established, participants in this study struggled to explain, and arrive at, candidacy for other cancers:

I must admit in my naivety, I don't know what causes prostate cancer, cancer of the colon, all these, I don't know what's causing them. (Andrew 57, Affluent)

How do you take breast cancer? You can have someone who doesn't smoke, doesn't drink, doesn't do anything and yet they can take breast cancer, men and women. (Julia 65, Deprived)

The explanatory hierarchy, with smoking at the apex, allows for some cancer events to be easily accounted for. Other cancer events are more challenging. Given that causal links are not well-established for all cancer sites, candidacy is limited and restricted to those areas where links are clear. Other behavioural characteristics by themselves could not predict cancer candidacy.

10.6.3 The scope and limitations of candidacy: anomalous deaths and unwarranted survivors

According to Davison the explanatory model for CHD is 'wide'. Anyone can be a candidate. Davison provides examples of individuals, equally at risk, but at opposite ends of a spectrum: those who engage in no exercise or those who do too much, high powered executives prone to stress and manual labourers subject to over-work. This suggests that a wide range of behaviours can contribute to heart disease. Cancer was not described in similar terms in this study. If cancer sufferers did not smoke and led 'healthy' lives, the event was largely unexplainable, so in that respect candidacy was relatively narrow. It was typical for participants to identify sufferers that did not meet any candidacy criteria:

Oh God no, she didn't smoke, doesn't drink, eats well, exemplary lifestyle so to speak, and eh not conducive to cancer of the colon. (Andrew 57, Affluent)

We did have a dear friend who nobody looked after themselves better than this lady and she took cancer and she died. (Phyllis 58, Affluent)

I've a friend and to me she lived a very, you know, she ate well, she didn't smoke she just drank moderately had quite a lot of exercise she was out doors and she died of cancer (Elsie 62 Affluent)

What these extracts capture is an important feature of ‘candidacy’. According to Davison, individuals recognised that while those that engage in risky behaviours can be event free, equally those who ‘do all the right things’ continue to experience illness events. This serves to reinforce the fallible nature of candidacy. Although many participants offered examples of people that ‘ticked all the right boxes’ for cancer, the majority of the stories were of individuals who did not fit their previously conceived model. Therefore it is the fallibility of candidacy that is the overwhelming experience of cancer for participants in this study. Davison identified such cases as ‘anomalous deaths’ and many anomalies are found in participants’ narratives. In the following extract, Angus provides the example of two of his brothers, one of whom he viewed as the epitome of a ‘candidate’:

James was an ideal candidate, eh heavy smoker, heavy drinker, didn't really eat healthily, fish suppers, pies that sort of thing, fry ups. Joe's like me he's totally the opposite, don't smoke, drink occasionally ... red wine, fresh fruit, vegetables every day, wholemeal bread all that sort of thing, you know, exercise, kept fit and yet he's got this version of cancer. (Angus 57, Affluent)

Here, both candidacy and the fallibility of candidacy are captured succinctly. All of the extracts point to anomalous cases that went beyond simply avoiding risky behaviours. They were described as extremely ‘health-conscious’, as bucking a trend, as always having been healthy before anyone knew it was important to do so. Essentially, they appeared to be the absolute opposites of typical candidates. The appearance of cancer in this ultra-healthy group challenged the received wisdom of causes of cancer. The following series of extracts demonstrates the disparity between what participants now know and what they once thought:

I mean he's always been the fittest guy you ever met, you know, he was in the first fifteen in rugger at school and university and, you know, a runner and I mean I climb mountains he (leukaemia sufferer) does fell walking or fell running or whatever, you know. I mean he runs up the bloody things (laughs) but no he's always been really, really fit. (Colin 61, Affluent)

My husband has always had a really healthy diet from before I think these things were generally accepted. I mean he, all his life, he has eaten, and I mean he came from a family where they had a kind of healthy diet because he lived in the country, didn't have a lot of

money, um his father smoked quite heavily but his mother didn't. But, they ate, they grew a lot of their own vegetables and didn't probably eat a lot of red meat, because they didn't, you know it would be a kind of Sunday dinner kind of treat for them, so um, and eh, so relatively healthy. I mean not sort of sports fanatics but he's always been slim, he's never been over-weight, he eats a lot of brown bread and all the right kind of fibre, he eats a lot of fruit and vegetables, you know he ate brown bread long before it was kind of fashionable to do it, um, and doesn't really drink that much. So, you know, um if anything that's kind of going against the survey and I suppose that's reduced his chances so much, I mean I don't know very much about, um I mean, you probably know a lot more about, you know being genetically disposed towards certain cancers, um, but no, it's a complete mystery with him. I mean he, as I say, he'd sort of followed all the rules and did all the right things and still got cancer, which I think in a sense, to me kind of fosters maybe a wee bit more of a fatalistic attitude towards myself. (Lisa 45, Affluent)

One of these people that was extremely healthy she was vegetarian, you know, she ate all the right foods, she exercised, they were Liberal Democrats they used to go all round Falmouth in Cornwall delivering leaflets and you couldn't have met a woman who was more healthy and health conscious and always had been. Really you couldn't have met a more health conscious woman than auntie. (Janet 47, Affluent)

She didn't drink you see that's forty year ago we're talking about right enough. My auntie Bessie didnae drink, she didnae smoke it was just her and her husband and the one son. She'd worked all her days till she got married and then had her son and after she had that, after she'd had her son she concentrated on her house, her home, her home, her husband and her son. (Rose 61, Deprived)

I found oot like that lassie that didnae drink, didnae smoke got it I thought she's the last person I would have thought that would have took it because at that time they were saying the smoking causes it. And I knew that lassie didnae drink, she didnae smoke neither she did and she didnae go intae a pub where people smoked either so I knew nothing like that and I thought she's the last person I would ever have thought would have caught that. (Patricia 62, Deprived)

I'd an uncle who died of throat cancer last year at 50, em so that was a shock and he was a non-smoker, never smoked in his life and very fit, healthy man. Didn't work in a smoky environment. That was a shock, that was a real shock and that was a kind of turning point for me, where I thought well actually that can affect anyone as opposed to lifestyle. Both my in-laws smoked so I suppose you kind of thought well your risk is much higher but this uncle of mine was one of the fittest, healthiest, body-conscious men I've ever known in my life. (Emily 37, Affluent)

The narratives borrowed for these examples all leave previous health status unquestionable. All these cancer sufferers were healthy and fit and yet despite this the cancer event occurred. The extracts also show participants' surprise and how in some cases they have changed their views. The extract from Lisa indicates that her very recent experience of cancer via her husband has forced her to reappraise her entire cancer belief system, and concludes that her attitude is now fatalistic.

10.6.4 Challenges to candidacy: triggers

The extracts above demonstrate that such cases forced participants to reassess their explanatory models and pursue other possible aetiological explanations. Reworked models included genetics, secondary events and trauma, both physical and psychological. As outlined in the previous chapter, many participants, particularly those that lived in the deprived community, suggested the presence of a 'faulty' or cancer gene as a possible explanation. Rose is unable to provide a definitive cause but does introduce the idea of a set of dormant cells early in her interview:

No, I widnae say I would know what causes it. I've heard different theories of cancerous cells in your body that was one of the things I was, I don't know who told me that but somebody somewhere said that to me, that we all carry cancerous cells. Whether that's true or not and if you've got a weakness it attacks them, I was told that. (Rose 61 Deprived)

It is interesting that Rose, like many of the other participants, is unable to locate the source of this information. Although a number of different terms are used and the way in which, what Angus described as a 'ticking time-bomb' is set off varies, the idea is fundamentally the same. As Gary explains:

Like certain people might have the, like again, I'm talking in laymen's terms, it's like a gene where it might no be it might be faulty or might be waiting tae be whit dae you call this word noo like activated sort of thing, you know, and that might happen. (Gary 37, Deprived)

Clearly then the circumstances necessary for activation varied. Again this was a retrospective activity and as such tailored to unique personal situations. Nevertheless, participants applied a typical series of common 'triggers'.

Trauma, either physical, in the form of accidents or psychological in the form of stress, was thought to be a trigger or activator for a subsequent cancer event. During the interview Patricia made a link between cancer and accidents:

But every one of them, except maybe my young cousin, I know had been in an accident of some kind as I said my mum had that beaten up. And my dad had actually fell and broke his leg and then it was just healing when they found out he had the cancer. All the other ones, they've had an accident. (Patricia 61, Deprived).

For some participants the gene was apparent in everyone but for others it was only apparent in some individuals. Such an idea gives fuel to the idea of cancer families and also helps account for unwarranted survivors, namely those who behave badly but 'get away with it' regardless:

I know and that's when I kind of think is there something in the body that maybe I don't know, that maybe triggers cancer or I think everybody's open to it no matter how healthy you are or whatever. (Karen 25, Deprived)

I think everybody probably has, but I think some folk have a bigger chance because of, maybe their background or their genes if you like. Well maybe the background they come from, I mean if their father had married someone else or their mother had married somebody else, it may have been a different medical outcome but then there are people, you know the lifestyle, there are people who have a healthy life style and can develop it. But maybe they would have developed it sooner, if they hadn't had that, you know. (Kathleen 68, Affluent)

I think, I think most people has got that in them and it just takes a certain something, maybe something that's no healing right, maybe you've had an accident and it's no healing right, things like that maybe. (Lorna, 57, Deprived)

I think it's genetic I do, I've got this strange idea in my head that really, really it's there in everybody but it's just something, you know, it is there and it'll kick in something will just trigger it off at some point. (Pauline, 57 Deprived)

So although cancer candidacy in one respect is narrow, the faulty gene supposition renders it even 'wider' than in Davison's original scheme. The idea that cancer is 'in you' lying dormant, has been reported many times (Cornwell 1984; Calnan 1987; Mullen 1994; Scanlon 2006). While Davison demonstrated that almost any characteristic could suggest CHD candidacy, the participants in

this study describe an explanatory model that is fundamentally a quasi-scientific presentation of 'luck'. If triggers can take many forms, including behaviour, the appearance of cancer is entirely random. Participants possess a customised model that can explain any case, even the most unlikely. Such a model provides a legitimate reason for each event encountered. The idea of trigger is akin to the links between cancer and secondary events that was uncovered by Blaxter (1982). The extracts also demonstrate that those in deprived communities were more likely to introduce the idea of dormant genes or cells and triggers in aetiological explanations of cancer. A degree of fatalism is attached to the idea that dormant cells and triggers explain cancer. Often it is assumed that working class fatalism is a particular barrier to health promotion and the engagement with good lifestyle choice (Balshem 1991).

The corollary to the anomalous case is the unwarranted survivor, which equally challenges established explanatory frameworks. Unwarranted survivors are those who 'do all the wrong things and get away with it'. While anomalous cases formed a significant part of many of the participants' stories about cancer, unwarranted survivors did not feature so strongly. Most participants, when asked, could provide an example of someone that they believed had failed to 'look after themselves' but had managed to escape cancer or other serious disease. A number of participants thought that this was extremely common:

I'm just saying that any illness as you rightly said are going along two or three stones overweight, smoking and they get off scot-free, good luck to them I don't grudge them that (Eileen 72, Affluent)

Most of them (clientele in social club) were walking adverts for cancer (Laughs) most of them are still going. (Emily 37, Affluent)

(Laughs) I can think of one particular person who to me has not had a healthy, mind you he's in his sixties and he's not had cancer. He smoked, drank a lot, still does as far as I know, and eh I don't think he really bothered too much about food didn't eat very well and he seems alright. (Elsie 62, Affluent)

74 and he's smoked fae he was a teenager, in fact pre-teens he smoked. I think he smoked when he was 12 my Dad's a kinda walking miracle cause he's like, fried foods, and he's got angina. (Gary 37, Deprived)

The extracts show that often the description of unwarranted survivors took on a humorous tone. While Davison found that candidacy for CHD was often related with humour, in this study humour was reserved for unwarranted survivors in discussions about cancer. The idea that cancer is not something to be joked about once more symbolises the fearful attitude towards cancer prevalent in modern society.

Participants could not explain unwarranted survivors. No justification beyond 'luck' was offered. Health education messages were not discredited by the existence of such individuals and many participants were cynical about the significance placed on them:

That's just, you've won the lottery, you know. You've been lucky, we have all read in the papers people who say, I've been a heavy smoker all my life, I'm perfectly alright and this sort of thing and therefore all this stuff about smoking and lung cancer is nonsense because I've beaten it, well these people have just been lucky it seems to me. Doubtless there are causal factors, of which I am unaware, which would explain why they have been lucky but I think the ordinary man or woman on the street would think, well, old Joe has been pretty lucky, hasn't he, like men who went through the first world war in the trenches and emerged totally unscathed at the other end. (Murray 83, Affluent)

It's crap, it's crap and okay there are survivors and there are exceptions. Well I mean it's not a rule that if you smoke you die of cancer I mean so there will be people who can say 'I'm ninety-five and I've smoked forty capstan full strength a day for the last eighty years and look at me'. But that's not an argument of anything is it? (Colin 61 Affluent)

This insight, that, what Davison termed Uncle Normans (Davison, Frankel & Davey Smith 1989), are simply epidemiological aberrations, has been found elsewhere. Emslie reported similar findings in their west of Scotland study on heart disease (Emslie Hunt & Watt 2001a, 2001b; Hunt, Emslie & Watt 2001). Their participants were aware that such aberrations should have little impact on the perceived importance of healthy behaviours

10.7 Individual vs. population risk

The above extracts show that some participants were sure that while for some risk behaviour had not been damaging, this could not be extrapolated to the

wider population. Such an understanding was not widespread among participants. A number of participants, while not dismissing the significance of tobacco, believed that “it must be more than cigarettes”. It was customary for participants to fix on the cases known to them and extrapolate to the wider population. Julia failed to account for her sister’s oesophageal cancer in the context of known risk factors and presumed that the information was ‘wrong’, rather than accepting flaws in bio-medical explanations:

I don’t honestly know if lifestyle or, likes of my young sister smoked, she smoked from when she was about 11 but she didn’t take cancer in her lungs she took it in her oesophagus which they say is drink related and I’ve got another young sister who is a recovered alcoholic and smokes like a chimney, she’s fine, she’s well, so how do you associate it? (Julia 65, Deprived)

10.8 What evidence is important? Formulating a model of candidacy

Previous chapters and sections within this chapter have shown that a wealth of information is integrated into participants’ models of cancer beliefs. Further, the manner in which participants develop an ever-changing personal evidence base is sophisticated and personally logical. Clearly there are similarities between the data generated from this study and the lay epidemiology model first described by Davison. Yet the basic scheme that refers to the way in which information is gathered and processed, is merely one component of Davison’s theory. Deeper within the theory lie a series of related and essential elements, principal among them is candidacy. Coronary candidacy, while no doubt a sophisticated amalgam of information, does as Davison conceded, incorporate many of the risk factors found in epidemiological models. When arriving at a judgement of coronary candidacy personal behaviour was first considered. Invariably an estimate was made based on physical stature. Other factors like family history, employment and temperament were also sought. Rarely however do lay epidemiologists have to look beyond well established risk factors to arrive at a candidacy judgement. Cancer candidacy is at once more simple and more complex. Evidence of smoking status was essential but many of established epidemiological risk factors are poorly recognised. Smokers were identified as the only true candidates. It was rare for participants in this study to highlight any non-smokers as candidates. While a healthy lifestyle was judged important,

few unhealthy non-smokers were identified. As has already been highlighted a handful of participants were appreciative of additional risk factors like diet and exercise and these were drawn on to arrive at a tailored candidacy model. Yet, obesity for example, which is an established risk factor for cancer and CHD, seems only to feature in coronary candidacy.

10.9 Personal responsibility and risk elimination in the face of luck

Though the influence of luck in cancer events was frequently stressed, this did not engender feelings of abandon with regard to health behaviours. As the following extracts show:

My feelings now are that a lot of it is probably luck, if you like, you know, almost predisposed that you're going to get it or you're not going to but I think there are factors that can, you know, put you at a higher or a lower risk, if that makes sense. I think you can kind of, there are things you can do preventive, but that's not a hundred percent guarantee that you're not going to have the disease basically. (Emily 37, Affluent)

I think, you know, it must be a combination there's a lot of genetic links as well and they say that if you have a genetic link of breast cancer in your family then don't smoke, don't make it worse for yourself, you know. Em, don't drink too much alcohol, you know, if there's bowel cancer in the family cut down on red meat that kind of thing. So I suppose you've just got to be aware and cut down on your risks as much as possible. Look at your diet and look at your lifestyle, look at exercise. (Janet 47, Affluent)

What the extracts from Emily and Janet show is that they simultaneously provide luck with an important role in their explanatory model but also imply that luck can be manipulated. Emily's idea that individuals are pre-disposed to cancer echoes Calnan's (1987) finding among women in his sample. Like Calnan's cohort, Emily lives in the affluent community and Calnan believed that predisposition was distinct from 'its in us all', which he found was common in women from social class IV and V. Arguably however the ideas are the same but articulated differently. When discussing the importance of luck and fatalism, Davison reported that participants in his study did not greet this with absolute fatalism. Rarely did fatalism encroach on behavioural choice. Rather it was an

understanding that not everything could be controlled (Davison, Frankel & Davey Smith 1992).

The above extracts, and Davison's findings, hint at the almost universal notion that disease risk cannot be eliminated. This is contrary to what Davison suggested regarding the common currency of prevention of CHD. For participants in this study, following a healthy lifestyle offered no immunity to cancer; it simply served to reduce one's risk. This idea was found repeatedly within interviews:

You can protect yourself, doesn't mean that you won't get it, but you can try and do what you can to, to minimise the risks. (Kathleen 68, Affluent)

Em, I think you can take steps to reduce your risks but I don't think that you can, it's a difficult one ... because I don't have cancer I would probably say that you could prevent it but I think if I was put in that uncle's position I would be saying "Well I did everything, I did the text book of what to do to not have cancer and I've still got it." (Emily 37, Affluent)

In the following extract, Lisa, whose husband had recently been diagnosed with cancer, describes a family conversation the previous evening, outlining how she communicates risk to her young children:

Funnily enough we were talking about this last night because there was a news item about um, the usual kind of thing diet and exercise.weight, not just obesity, but even a very minor level of being overweight can affect your chances, you know and fatty food so they were basically talking about diet and exercise and you should be as thin as you possibly canSo yes, we were talking about this last night when we were eating our dinner because I was saying to the boys, I mean I have always been very open and honest with them about cancer, I mean we don't shy away from the topic at all and I was saying given your genetic disposition, I mean we don't know how much of a link there is genetically but if there is there's nothing you can do about that, you can't change that, your genetic makeup but what you can do is influence it by diet and exercise, you know. So, you should try and do whatever you can in your lifestyle to try and reduce your chances. (Lisa 45, affluent)

Gary made a distinction between behavioural risks for some cancers and other cancers that could not be avoided:

So I think, my personal opinion is, the way I think about in my heid obviously. Is that there is certain types of cancer which you can avoid but there's other types of cancer that it disnae matter how you live your life you're gonnae get it, you know. Just because of the way maybe and I keep saying genetically, you know, I'm using the word genetically and I don't know much about it, you know. (Gary 37, Deprived)

Estimating one's own risk of cancer appeared to be removed from the reality of actually considering getting the disease. It was difficult to engage participants in such a conversation and some participants seemed superstitious at the mere thought of it. For example one participant's mother who was present at the interview but did not contribute simply said:

My granny used to say "if you fear it you'll get it". (Marjory 78, Deprived)

Yet many also approached it with bravado, 'what will be' attitude:

C'est la vie, if I get it, I get it (Jessie 63, Affluent)

Well, I think if it's coming, it's coming (Pauline 57, Deprived)

Here the ideas around 'what's for you won't go by you' were touched on. This was a fatalistic view that if cancer was in your 'destiny' it could not be controlled. A number of participants did say 'it won't happen to me', 'that's something that happens to other people' and one, Angus, claimed that if he got it he would fight it and win. Yet Angus was wedded to the notion that there is a faulty cancer gene that requires activation, suggesting that he acknowledges the role of luck and uncertainty in the progress of cancer. Nevertheless, he was also clear that he was doing everything he could to reduce his risk, given his family experience, and he employed militaristic metaphors to emphasise his ability to defy luck.

10.10 Fatalism

Although Davison's original paper on lay epidemiology did not discuss fatalism, it was introduced in additional papers that drew on the same data. Participants, both in this, and Davison's study, discussed disease risk in fatalistic terms. Often fatalism has been held responsible for the failure of health promotion messages

in some communities (Pill and Stott 1982, 1985, 1987). However, the assumption that fatalism is associated with apathy is misplaced. In this study the discussion of fatalism, or more properly the randomness of disease, is realistic and confirms the distribution of disease described by epidemiology. Many of those in a high-risk group will remain disease free and vice versa. Therefore to settle on the notion of the importance of the unexplainable is not fatalistic or irrational but instead based on observation. Moreover, participants in this study often discussed the perils of being pessimistic or ignoring advice, as the following extracts illustrate:

That's when I said before the fourth one (risk factor) would be random, you know just accept it, you know a bad thing is to be fatalistic, because if you're fatalistic, its not good for you long term, you know, people who are fatalistic don't survive as long as people who are positive but I'm quite fatalistic in the randomness of illness. (Andrew 57, Affluent)

Well, if your name is on the bomb its going to get you so there's no point going down to the shelter, I suppose it's a form of fatalism, yes, I suppose it is. That shouldn't mean that one shouldn't take all sensible precautions against it of course. (Murray 83, Affluent)

10.11 Chapter Summary

Fundamentally, lay epidemiology refers to the method of collecting and processing information to arrive at an explanatory model of disease. Davison and colleagues reported information from many layers of social relationships and interactions were utilised. Data from this study confirms that a similar method is employed in relation to cancer. Cancer events are experienced within families, are discussed in social groups, are presented by the media, albeit within limited narratives. Throughout the interviews in this study all of these sources are cited naturally and clearly all of the layers have a role. According to Davison the information is digested and provides the means to make risk assessments by arriving at coronary candidacy. Candidacy, Davison described as a cultural mechanism and data presented from the ethnographic study in South Wales continues to reflect what is easily recognisable as the everyday way that CHD is discussed. Such everyday discussions mirrored mainstream epidemiology. Data from this study shows that though there may be a similar everyday talk associated with cancer, candidacy rarely emerges. The notable exception to this

were smokers, who were easily marked as candidates. The success of the coronary candidacy idea is aided by a widespread recognition and acceptance of risk factors for CHD. With the exception of smoking, and to a lesser extent sun exposure, cancer does not benefit from equal levels of understanding. As such candidacy is a more elusive concept. The reasons for this are many. First, in comparison to CHD, cancer is perceived to be a more complex disease. Allied to this is that the lay public link a set of well-established risk factors to CHD. Smoking excepted, cancer risks are less well appreciated and are often, at least in the public's mind, subject to change. Finally, cancer, unlike CHD is a feared disease. Davison highlighted the different perceptions of CHD and cancer:

“ ... it should be noted that sudden heart stoppage is something of a preferred form of death. ‘Dropping dead’ from a heart attack is widely seen as a quick, natural and relatively painless death (in comparison with cancers, respiratory disorders and traumatic accidents)” (Davison, Frankel & Davey Smith 1991:10)

11. Discussion: Reflections on Research Questions

11.1 Introduction

This chapter will first offer some reflections on the study as a whole and consider the main strengths and weaknesses of the study. The discussion will then turn to the specific research questions detailed in Chapter 4, before going on to reflect on other important study findings.

11.2 Reflections on the study

This study set out to uncover and explore ordinary views of cancer. Though it did not seek to be generalisable, inherent in its aim was discovering a typical view of cancer, if one existed. The suitability of the sample population was therefore vital and many of the strengths and weaknesses of the study are to be found in the study sample. It is a merit of the study that it attempted to access an 'ordinary' view of cancer. The extent to which any patient population can truly be regarded as 'lay' has been reviewed by Shaw (2002), who suggested that patients become experts over the course of their illness. Indeed, modern health policy encourages the development of the 'expert patient' (Department of Health 2001). Although sampling randomly from a general practice population, which excluded cancer patients, might have generated a useful sample and with hindsight would have eased the sampling process, it was felt that it may compromise the 'lay' aspect of the study. Distance from mainstream health professionals and healthcare providers, was important. Moreover, the study aimed to access community views, if these were present. A general practice sample, though located in a geographical community would not guarantee people with a sense of community. By sampling through community groups like churches, tenants associations, community councils and leisure based groups, study participants had social networks that included others from their local communities. Groups with a health focus were deliberately avoided, again to distance the study from 'healthcare' and those with a particular interest in health.

Sampling via community groups however was challenging, particularly in the deprived community. A wide range of organisations were contacted in both areas but few agreed to participate. As outlined in Chapter 6 on methodological design the original target was to carry out 40 interviews, 20 in each community. Unfortunately this was not met after extensive efforts to bolster numbers. A total of 31 interviews were undertaken.

In an age where a wealth of health information is available to the general public and is constantly increasing, achieving a genuinely lay viewpoint is unlikely, or arguably undesirable. If study participants were truly blank slates they would have had little to offer. Often the patient perspective is assumed to be the lay view. Few studies aim to report an 'ordinary', but crucially, non-patient view. Many of those interviewed did possess what they described as a 'close' experience of cancer through that of a relative or friend and such proximity could potentially place them in an expert position. However, given the high incidence of cancer, recruiting a sample that had no such proximity, might be problematic. Indeed, it could be argued that this does reflect an ordinary or typical view. Any entirely self-selected sample is bound to attract those with an interest, irrespective of subject matter. It is worth noting however that one volunteer withdrew because on reflection she judged it best 'not to talk about cancer', not because it was upsetting but for more superstitious reasons. Admittedly, some may find cancer a distressing topic for a range of reasons. Other features of the sample are also worthy of mention. Although the ages of the sample ranged from 25 to 83, most of those interviewed were in the 55-70 age-group. While this allowed participants to offer insights into the changes they had witnessed in cancer outcomes over half a century, the study might have benefitted from the views of younger participants who may have normalised the more recent positive advances in cancer treatment and outcomes. Although small, the sample included both men and women.

Participants were accessed via community groups in two communities in Glasgow, one affluent, one deprived. Due to the difficulties associated with sampling, interviews were undertaken almost consecutively, first in the affluent community and then the deprived. As an iterative method of interviewing was followed some of the issues raised in the earlier interviews were fed back only into the interviews in the deprived communities. It is not certain whether some

of the slight nuances between the two communities were simply an artefact of the interview process.

11.3 Reflections on the research questions

11.3.1 What are typical views of cancer?

Although participants' experiences of cancer varied widely, a number of typical views of cancer were expressed. Most commonly cancer was seen as something to be feared, a view which has been widely reported (Sontag 1978;; Herzlich & Pierret 1987; Patterson 1987; Scanlon et al 2006). Many of the study participants were able, because of their age, to reflect on how views of cancer had changed. While cancer was once the stigmatised 'Big C', rarely discussed and poorly understood, it now represented the possibility of a more hopeful outlook. Medical advances have precipitated a shift in metaphor. As both Lupton (1994) and later Ehrenriech (2009) have demonstrated the 'hope' and 'positivity' narratives now dominate the culture of cancer in an attempt to counteract the ever-present fear. This contradiction is reflected in these interviews. The data generated in interviews illustrate a largely superficial hope because cancer was represented by a handful of typical, less positive narratives. Principally, cancer equals tragedy. For some this held true even if the eventual outcome was positive. Often, though not always, tragedy was reserved for the young rather than old and most participants could give pertinent examples of tragic events as evidence. Cancer in older adults was viewed with more ambivalence. This echoes findings in Emslie, Hunt and Watt's (2001a) work where similar views were expressed about CHD in the elderly. In their study CHD was thought to be a relatively quick and painless death, and viewed by some as the 'way I'd like to go'. This is not reflected in discussions about cancer, where the two key disease experiences were either a long, drawn out suffering, or a quick and sudden shock. Cancer has two important facets that set it apart from the typical view of CHD. First, cancer is not immediate even if it results in a relatively 'quick' death. Sufferers must confront their diagnosis. Second, cancer is believed to be painful. Although CHD is undoubtedly painful, it is immediate and assumed to be over in minutes. While shock could equally attend an unpredicted coronary event relatives are assured that their loved one was spared 'suffering'. A further common cancer narrative was that of unpredictability. Indeed, the two typical

illness trajectories described for cancer serve to emphasise the unpredictable nature of the illness. In the 'quick' narrative a seemingly healthy person falls prey to cancer quickly, leading many to assume that they 'had' cancer 'without knowing it'. Therefore it can strike at any point with symptoms arriving only 'near the end'. This adds to the supposition that cancer is ever-present in everyone simply waiting for an appropriate trigger. In the 'long-drawn out' narrative individuals are often reported to have lasted longer than predicted, so again cancer has even defied the professionals. Linked to this was the dread associated with recurrence. Many participants knew of cases where patients were apparently cured only for a 'quick' recurrence to ensue. While it was widely accepted that 'cures' were possible, this was thought unlikely in the event of a recurrence. Yet there was no sense of the recurrence being predicted. Even in positive stories the unpredictableness of cancer is discussed. Surviving in spite of bleak prognoses was equally random. Participants often stressed the uncertainty that came with cancer. Arguably this was a novel experience for those that had grown-up in a climate where cancer meant certain death. The uncertainty produced by advances in treatments resonates with Comaroff et al's (1982) work on childhood cancer. They demonstrated that it is the lack of certainty that is most challenging for families and that the hope narrative, a consequence of improvements in survival, augmented rather than ameliorated distress. They claimed that those questions that remain unanswered, however small in the context of advances, are more frightening by virtue of their unfathomableness.

As well as being unpredictable cancer is also assumed to be common, with an ever-increasing incidence. This perception reflects epidemiological reality. As many as three in five of us will suffer some form of cancer and incidence is increasing. However, much of the epidemiological reality can be attributed to a growing ageing population. As already noted cancer is assumed to be tragic but only in young people, and it was rarely described by participants as a disease of older people. One participant believed that cancer was as common as the cold, another referred to it as an epidemic. Both metaphors portray the widespread fear of cancer. Epidemic, in particular, conjures images of a disease out of control, while curing the cold has long defied experts.

These typical cancer stories are told in common cancer talk. Many of the familiar metaphors associated with the disease appear liberally throughout the interviews. In particular military metaphors were used frequently. More striking was the way in which cancer patients were discussed. The particular importance of maintaining a positive outlook throughout was raised repeatedly. This cancer language also incorporates expert jargon about treatments and outcomes. While Armstrong & Murphy (2008) reported that their participants deftly intertwined lay and expert terms throughout their interviews, theirs was a patient population. Participants in this study, like those in Emslie, Hunt and Watt's (2001a) study, used lay and expert terms interchangeably when discussing disease.

As well as typical views about how cancer presented and progressed, there were also typical views about cancer aetiology. Participants were clear that cancer was a disease with many different causes. Behavioural risk factors were invariably the first to be mentioned, specifically smoking. Smoking was the only behaviour discussed in all interviews. Beyond that, understanding about risk factors was haphazard. Only a handful of participants could be regarded as very well informed about the various behavioural risk factors linked with cancer. Instead most possessed a view of what constituted healthy or unhealthy lifestyles, and presumed that unhealthy behaviours were linked with cancer.

This applied more to diet and alcohol consumption and less to physical activity. Balance was central to the maintenance of a healthy lifestyle and many stressed that excess, either of good or bad behaviours, was unhealthy. None of the participants were wedded to the idea that behaviour alone, with the exception of smoking, could explain cancer causality. Many of the widely reported controversial risk factors like pollution, power lines, chemicals and pesticides and mobile phones were introduced. All were regarded sceptically and cancer clusters were largely dismissed. Yet, despite scepticism of individual agents there was the sense that cancer was a 'modern' disease and though none of these elements alone could offer aetiological explanations, together, these modern phenomena could be at least partly responsible. Invoking modernity as a catch-all explanation is found in many studies of health beliefs in diverse social groups (Herzlich 1973; MacFarlane & Kelleher 2002; Scanlon et al 2006; Salant & Gehler 2008).

What is interesting is that participants held a contradictory view of history. Initially they talked about the Big C and the stigma associated with cancer which referred back to a time when cancer was rarely talked about even within families. Cancer was feared because it was poorly understood, and crucially people were unsure of its cause. It was evident in the interviews that changing attitudes towards cancer were welcomed and none of the participants were wistful for a return to such times. Yet the advent of openness and freely available information brings uncertainty. There are more cases available to discuss, many more reported risk factors but few definite causal explanations. Many of these apparent risk factors are features of modern living, so many participants were wistful for the return to a purer life, where cancer had fewer opportunities to develop. Instead of isolating individual risk factors participants talked about risk more holistically. Often this was expressed as an unhealthy lifestyle, but often this extended to an unhealthy way of life. This confirms Herzlich's (1973) early work where city-dwellers assumed that life in the countryside was more health-giving and Salant & Gehler (2008) conclusion that participants were nostalgic for a time that was thought to be risk free. What these studies have in common, including this one, is the identification of modern dangers, which went beyond unhealthy behaviours and extended to stress, pesticides, convenience foods, and pollution. The perceived risks associated with all of these dangers, not individually, but in totality, leads to the link between cancer and modernity. Essentially the benefits associated with modernity - scientific advances, and improvements in survival - must be offset against its inherent dangers.

This study did uncover typical views about cancer. Despite medical advances cancer continues to induce fear, principally because it remains uncertain and unpredictable. From this perspective it inhabits very different ground when compared to CHD. CHD has been found to be linked with a 'good' death and cancer is in direct opposition to this. Much of the uncertainty associated with cancer generally is a result of continued uncertainty about causality. Smoking is the exception which was rarely doubted as an important factor. Other risks were less well understood but there was a tendency to resort to a more holistic view of causality that placed modern living at the centre of aetiological explanations.

11.3.2 How important are personal, social, cultural, biomedical and environmental factors in the formulation of beliefs about cancer and cancer risk?

The data generated in this study shows that information is gathered from a variety of sources, including personal and social networks, health education and the media. Personal experience is clearly important. This is axiomatic. Direct experience provides evidence for stories and participants in this sample used stories to illustrate their expressed beliefs. Proximity to cancer was highlighted as an important marker for the levels of detail offered by participants' cancer narratives. Equally though, distant proximity provided narratives from wider social networks that could have lasting impressions on beliefs about cancer and explanatory models. Much of the literature on health beliefs suggests that health is only confronted when problems arise but people naturally talk about others' events and problems. This talk also provides material to feed into explanatory models and participants frequently describe this process. Moreover, they show that the models are dynamic and updated in light of new evidence. Social networks though, like the media have a tendency to focus on the newsworthy and the tragic, and it is this type of narrative that remains in the memory. These are also the stories that are likely to be passed on, making the lay observer akin to a tabloid journalist, rather than an epidemiologist, in this context.

It is clear from this study that cancer has a strong cultural resonance. Just as Davison found that talk about CHD was easily recognisable and familiar, the same is true of cancer. Arguably though the two are represented by quite different cultures and this has consequences for the way in which each disease is understood. Personal, social and cultural tragedies are talked about amongst families, work groups and in the media. One need only think about the case of Jade Goody to see how cancer can be dealt with in the media and irrespective of the effect of that episode on attitudes to cervical screening and uptake (Metcalf, Price & Powell 2010) it was likely to provide cervical cancer with the more publicity than any health promotion activity. Although Jade Goody's death happened after the interview process in this study, it was evident that media stories had a far reaching impact. For participants in this sample, passive smoking was synonymous with Roy Castle, so much so that stories similar to his, of working in smoky environments, provided explanations for familial cancers.

There can be no doubt that the media have a key role in shaping and sustaining the cultural position of cancer. A useful example is the understanding of the role of genetics in cancer. Henderson and Kitzinger (1999) attributed the over-estimation of the genetic element in breast cancer by women in their study to the way in which the media covered the subject. Coverage can distort the image of the 'everyday' experience of cancer. As was shown in Chapter 3, while once the American Cancer Society attempted to persuade the US public that cancer was not a disease associated with old age they have in essence become victims of the success of this campaign. Many awareness studies highlight the failure of the public to make links between cancer and ageing (Breslow et al 1997; Paul et al 1999; McCaffrey, Wardle and Waller 2003; Keighley et al 2004). Many different narratives were offered in these interviews, and most referred to older people, yet age was rarely mentioned as an important risk factor.

Biomedicine provides the backdrop for the understanding of cancer. Germs, cells, and the biology of cancer are well recognised. As well as an understanding of the biology of cancer, biomedicine also plays another key role. The association between cancer and genes was important and this was understood in two distinct ways. First the idea of heredity was common and there was widespread recognition about the links between breast, ovarian and colorectal cancer and familial genes. Although previous studies have pointed to the over-estimation of genetic factors and familial risk amongst women, this was not the case here. A number of women in this study were clear that there were different types of breast cancer and their risk was not heightened by virtue of their familial experience. However there was a belief, expressed by many in this study that cancer families could be identified. This echoes other work in the west of Scotland and the UK that reported the identification of disease specific families (Emslie, Hunt & Watt 2001a; Scanlon et al 2006). In this study, this was more likely to occur among those who thought they did not have cancer in their 'family'. The explanations for this are likely to be twofold. First, those in 'cancer families' were more likely to have paid close attention to their risk estimation in light of this information and so were simply better informed about the reality of genetics. Second, placing oneself at risk was challenging and having no cancer in the family provided much needed distance. Genetic understandings extended beyond familial links, however. The frequency with

which participants expressed the view that cancer takes the form of a faulty gene that can be activated by varied factors was unexpected. The language used differed by participant but they were essentially referring to the same concept. It is worth noting that some participants believed that not everyone was born with the gene. Regardless, the presence of a dormant gene that can ‘trigger’ cancer at any point provides a convenient catch-all aetiological explanation. It is essentially a quasi-scientific reworking of luck. Many studies have previously found versions of what is essentially the same aetiological explanation (Cornwell 1984; Calnan 1987; Mullen 1994; Scanlon 2006

The way in which ordinary views of causality and risk are expressed is important. Rather than talking about risk factors in a biomedical manner, participants tended to discuss all risk factors in terms of ‘causes’. For example, it was not uncommon to say ‘everything causes cancer’, or ‘mobile phones cause cancer’. Although this distinction may seem semantic it is important in the context of lay epidemiology. Risks are based on probability, while cause is definite. According to lay epidemiology, risk estimation is based on observation, and the implication of that is that the lay public are likely to remain unsure about the validity of risks that have not, for them, made the transition, via observation, to cause. So it is clear that most people will unreservedly accept the risks associated with smoking because most people will have known someone who smoked and died of a smoking related cancer. It is easy therefore to establish cause, and consequently accept risk.

11.3.3 Does lay epidemiology offer an aid to our understanding of beliefs about cancer and cancer risk?

At its most basic level the lay epidemiology model describes the way that individuals gather and reorder information to arrive at their own explanatory model, and estimate risk. Clearly participants in this study dealt with information in much the same way as described by Davison and colleagues with reference to CHD. Throughout the interviews participants talked about the development of their explanatory models. Those events in the family had most resonance but some explicitly talked about seeking out information in response to family events. Others talked at length about the examples of individuals in their wider social circles and the media. Often all of these layers of information

were included in one story. So both proximity and distant proximity were important which confirms the method of data synthesis described in the original lay epidemiology model.

Davison is not explicit about the fixedness of beliefs about CHD. Coronary candidacy is so successful because of a universal acceptance of CHD risk factors that have remained unchanged. Information about cancer, partly because of its multisite and multi-causal nature, gives the impression of being ever changing. This flux is reflected in ordinary explanatory models. Participants in this study describe models that adapt to incorporate new material and evidence. Indeed, because cancer is a multi-site and multi-causal disease it demands more from its explanatory model. Each individual model, while holding typical information, is nuanced to reflect personal experience. Though this is likely to be true of CHD the potential for a convoluted model is enhanced with cancer. It could be argued that just as Davison's model demonstrated the sophistication of ordinary views, the findings from this study highlight both the sophistication and complexity demanded of the lay epidemiologist when arriving at an explanatory model of cancer.

How beliefs are formed and developed is only one element of lay epidemiology. Candidacy, anomalous deaths and unwarranted survivals are vital to the operation of the model. These will now be looked at in turn.

11.3.3.1 Is there any notion of candidacy in relation to cancer?

Davison described candidacy as the 'cultural mechanism' that allowed estimations of risk to be operationalised. As such, the candidacy model relied on CHD having a strong and familiar culture. It clearly does. Many studies (Preston 1997; Wiles 1998; Emslie, Hunt & Watt 2001a; Frich et al 2007; Weiner 2009) have shown that a strong recognisable candidate apparent in beliefs about CHD. Emslie, Hunt and Watt (2001b) demonstrated that women were missing from the model, and Ruston and Clayton showed that women underestimated their risk because they assumed that only men were coronary candidates. All of this confirms what Weiner (2009) described as the 'tenacity' of the coronary candidate.

Cancer too has, as this study reflects, a strong cultural base and a common talk. Yet it is precisely this culture that may impede the identification of a cancer candidate. There are areas where candidacy is strong. Smokers were cancer candidates. Much like the discussion of CHD sufferers' physical stature, smoking status was central to any discussion of cancer candidacy, though smoking does not provide an immediate visual cue. Leaving smokers aside, are there other cancer candidates?

Within the original lay epidemiology model, although the coronary candidate was easily recognisable, Davison identified four different types of candidacy. Candidacy could be either retrospective or prospective and could be applied to oneself and to others. The strongest and most successful application was retrospective candidacy applied to others. A similar pattern emerges for cancer. Davison described candidacy as a 'wide' concept which was applied by scrutinising well-known risks and arriving at the most appropriate explanation. Such a discreet risk profile is not so well-known or recognised for cancer, so with the exception of smokers, endless possibilities combine to make the cancer candidate. In their study of candidacy and cholesterol, Clarke, Crotty, & Pearson (1997) found that their participants recognised a series of candidacy profiles that included an array of risk factors but the cohort failed to settle on one universal profile. Physical stature was included in all profiles. Smoking status was likewise consistent in the cancer candidacy profile, but unlike Davison or Clarke, Crotty & Pearson cancer candidacy profiles were not reached.

Using the candidacy model to assess the future risk of cancer was challenging for participants in this study. There are a number of possible reasons for this. First, cancer risk profiles are not familiar enough, with the exception of smoking. More importantly, as one participant stated 'you just don't talk about cancer in that way'. Again this is testament to the different cultural understandings of cancer and CHD in our society. Davison acknowledged that the term 'candidacy' itself may be problematic. Candidate is associated with elections, and to bestow candidacy on someone or oneself is to 'put forward', so essentially candidacy refers to nomination. You are proverbially throwing your hat (or in this case someone else's) in the ring. As Emslie, Hunt and Watt (2001a) demonstrated in their west of Scotland study, many of the participants reported that a quick

painless CHD event was their preferred 'way to go', no such parallel is drawn with cancer. Participants in this study were not comfortable 'singling out' those that might get cancer. Cancer is not a disease that you would wish for yourself or anyone else. Though, as already stated smokers were readily identified as candidates, as were those who were 'sun worshippers'. Arguably, the risks of both behaviours are so well documented that by continuing to participate in them smokers or sun worshippers are nominating themselves. Personal culpability is easily introduced into the candidacy model. It has long been established that the public separate disease into those in which sufferers are thought largely blameless and those which could be avoided if certain behavioural regimes were adhered to. Blaxter (1979) and later Cornwell (1984) found that some cancers were judged blameless, with the exception of lung cancer, where blame was apportioned to the sufferer. Davison suggested that it was 'common currency' that CHD was preventable through 'good' behaviour. Smoking was strongly believed to be a basis for candidacy, and although some in this study were keen to emphasise distance between smoking and cancer, no one denied the very clear links. Nevertheless, participants in this study seemed uncomfortable predicting the probability of future illness in those who in essence got ill 'though no fault of their own'. The corollary of this position is that candidacy raises fewer challenges when sufferers, or likely sufferers, are thought wholly responsible. The idea of highlighting someone as a candidate for a dread disease, particularly one that they are believed to have no control over, feels unethical. Indeed, perhaps reticence is experienced when making such judgements because candidacy could apply equally to the judge as well as the judged. Candidacy may not therefore be an entirely useful concept when considering beliefs about all cancers.

11.3.3.2 To what extent are anomalous deaths and unwarranted survivals employed?

Candidacy's failure to be as salient for cancer as CHD has obvious implications for anomalous deaths and unwarranted survivals. Given that smoking was seen as the primary risk factor, then most cancer deaths among non-smokers were anomalous. Indeed, even among some of the smokers, death was judged anomalous because the individual was thought to be otherwise 'healthy'. Candidacy for CHD was reached first by considering physical stature. Thereafter,

a wide spectrum of behaviours, for instance, too much, or too little exercise, were taken into account. Chapter 10 suggests that candidacy for cancer is similarly wide, especially if faulty genes that merely require triggers for activation are present. In this respect, everyone is at risk of, or a candidate for, cancer. Yet most stories were presented as anomalies. Therefore, the difficulties associated with establishing candidacy for cancer serve to increase the profile and number of anomalous deaths. Moral judgements were implicit in many of these narratives. These were 'healthy' people who did not deserve cancer, rather than cancer candidates. Only true candidates, by virtue of their behaviour were deserving of that label.

Much less common in this study was the evocation of 'unwarranted survivals'. In Davison's study this typical 'Uncle Norman' stereotype was introduced in humorous tones, and on the few occasions they were talked about in these interviews a similar humour and fondness was employed. However, this was an area of difference between the affluent and deprived community. Some in the affluent community, when talking about unwarranted survivors, stressed their uniqueness would not be borne out in statistics, others were generally disparaging. They discussed such individuals in terms of 'lucky fools'.

11.3.4 Do lay explanations view cancer as a homogenous disease or multi-site and multi-causal?

Much of the health beliefs literature reviewed in Chapter 2 found that cancer, in generic terms, was a feared disease. Rarely did this specify a cancer site. This study set out to explore whether cancer was typically thought of as one homogenous disease. Most participants talked about cancer as a generic disease, though admittedly it was first introduced into interviews as a homogenous disease. Early in narratives the catch-all label of cancer was offered and only on probing was the site, if it was known, disclosed. There were notable exceptions. One was breast cancer which was always given its full title, and it is likely that this reflects the media attention received by breast cancer (Gottlieb 2001). The other was non-smoking related lung cancer, which reflects the desire to distance the lung cancer sufferer from personal responsibility. The stigma attached to lung cancer has been previously observed (Chapple, Ziebland & McPherson 2004) and this too was found this study. Despite being the most common cancer, lung

cancer was rarely discussed. Biologically, cancer was seen as the one disease that affected different parts of the body, though a handful of participants made distinctions between leukaemia and other cancers. Cancer was seen as multicausal, even if these causes were poorly understood. Smoking was typically associated with all cancer sites. Often links between site and cause were made during the course of the interview and this was typically a commonsense view, for example, many assumed that diet and gastrointestinal cancers were linked. Proximity to cancer was influential here. Participants that had sought out information on specific cancer sites had an understanding of appropriate risk factors but this related directly to experience. This concurs with the idea of availability heuristics (Sanders et al 2007) because people draw on their direct experience to evidence their views.

11.3.5 Are there differences between beliefs in deprived and affluent communities?

Only subtle differences were found between those living in deprived and affluent communities. Views and experiences were similar across communities and often the key difference was the way in which thoughts were articulated. Proximity to cancer was the most important factor in levels of awareness, which were individually framed. Generally those in affluent communities had closer proximity to cancer and from that perspective appeared to have greater awareness. However, if a participant from a deprived community had close proximity, their level of awareness was similar to that of a participant with similar proximity in the affluent community and vice versa. It was the case though that those in the deprived communities were more likely to question the absolute risks associated with smoking, but more of them smoked or had smoked. Similarly those in deprived communities were more likely to suggest that cancer may have been caused by a faulty gene that required a trigger to activate it. However those in deprived communities were no more fatalistic as a consequence. In affluent communities the randomness associated with cancer was more likely to be introduced than the faulty gene theory. Arguably these concepts have a similar root. Both provide an explanation for the unexplainable but are expressed in different ways and far from being irrational, the trigger explanation is, in the context of cancer genes, a more rational response.

Given that risk behaviours are socially patterned (Wardle et al 2003), it may have been fair to suppose poorer overall awareness in the deprived communities. This was not the case. Awareness was highest among those participants that had experienced a close and anomalous cancer. None of the participants in the deprived community fitted this profile. Moreover, because the cancer disease experience is similarly socially patterned (Coleman et al 2004; Faggiano et al 1997; Shack et al 2007) and lay epidemiology claimed that community events were important, more differences might have been expected. If epidemiological patterns are used as a guide then those in affluent communities should have fewer observable cancer events on which to draw, and those observable events should have better outcomes than those in deprived communities. This epidemiological reality was not reflected in the interview findings.

11.4 Further reflections

11.4.1 Explanatory models

This study provides a clear insight into the way that people talk about disease. The idea that people seek explanatory models for illness (Kleinman 1980) and draw on a repertoire of beliefs to inform that model (Chrisman 1989) is not new. Yet, these studies focused on the reactions of patients and how they made sense of an illness. What this study adds is that ordinary, non-patient views of health are formulated in the same way and narratives of others - whether close or distant - are borrowed to fill that repertoire. Granted, Davison's lay epidemiology described the process of information gathering from numerous sources which are then combined to form an explanatory model. The original description suggested a static model. It may be that our understandings of the risks connected with CHD do not change and so the explanatory model is fixed. More is demanded when arriving at an explanatory model of cancer. It is likely that explanatory models will hold only until the next case is observed. Each new case is fed into a dynamic explanatory framework. The findings of this study capture the elaborate and highly developed nature of explanatory models of cancer.

11.4.2 Prevention paradox & fatalism

Lay epidemiology went beyond a description of the formulation of beliefs and the mechanism for risk estimation. Davison was clear that the concept could explain some of the shortcomings of health promotion. Davison demonstrated that the participants in the south Wales study had adopted many of the messages about CHD risk put forward by mainstream health promotion. Health promotion implements strategies at a population level. The population approach adopted by health promotion requires everyone to make behavioural changes in order to achieve even a slight benefit. However, in so doing, risk thresholds become lower and consequently many more people are now 'high risk'. The distribution of CHD events will continue to fall out with the high risk group, so more among the high risk group will survive. Such observations lead, according to Davison, to rational questions about the extent to which behaviours are genuinely 'risky'. Although candidates will succumb to CHD and non-candidates will not, the reverse is also true and it is this recognition that challenges health promotion. From the same data, Davison introduced the ideas of 'fatalism' and contended that fatalism, in all its forms, provides a reasonable explanation for an anomalous CHD event. Nowhere did Davison hint that fatalism challenged candidacy. Rather it appears that fatalism is as influential as candidacy in explaining CHD events:

"Accounting for the randomness and scatter that exist around the epidemiological trends is not a central issue for public health professionals. Rather, they deal with the trends themselves and concern themselves with taking action directed at amending a probabilistic future. Popular health culture on the other hand, cannot turn its back on any illness or death. Those which violate general principles must also be explained. It is within this context that an ethnography of fatalism is important, as it seeks to throw light on the cultural structures within which common, but apparently anomalous, events can be accommodated." (Davison, Frankel & Davey Smith 1992:101)

It seems then that for Davison candidacy holds steady, even when challenged by anomalies. Hunt and Emslie (2001) countered that those anomalies, particularly within the family, 'deconstruct' candidacy. Family events will be most influential and have the power to transform, rather than confirm, candidacy. The findings of this study show that these positions are not mutually exclusive. Naturally, a family experience of cancer is, as Hunt and Emslie suggested, more

than just an event that is fed back into an overall explanatory model of cancer. However, the event need not necessarily challenge candidacy. For example, if a case was described as anomalous by virtue of an apparently 'healthy' lifestyle of the sufferer, a re-evaluation of what constituted 'unhealthy' does not necessarily follow. Rather, as Davison stated, this anomaly emphasised the hand of fate. Certainly, knowing smokers who did not have cancer and cancer sufferers that had never smoked did not lead participants in this study to deconstruct the candidacy of smokers. Hunt and Emslie also suggest that uniquely rich information, which cannot be gathered from distant or fictional sources, is only available in the family setting. This insight, they contended, provides family members with the ability to be lay anthropologists rather than epidemiologists:

"The emphasis is not on isolating risk factors, but on contextualising, qualifying or even rejecting previously accepted risk factors or aetiological theories in the face of contrary personal experience. (Hunt & Emslie 2001:445)

Yet Davison made provision for this in two key ways. First, by stressing that the lay public see the fallibility of candidacy and second, by stressing the importance of fate. Although candidacy is not as powerful for cancer as it is for CHD both the fallibility of mainstream explanations and fate were often introduced in relation to known cases in this study.

Like Davison, Hunt and Emslie made a plea for health promotion to take cognisance of lay theories of health behaviour and consider motivations for behavioural change. The problems associated with the prevention paradox for health promotion were outlined by Davison many times and are echoed by Hunt and Emslie. Yet, Davison conceded when discussing fatalism that throughout the course of the ethnography in Wales he rarely found a participant that thought adopting healthy lifestyles were rendered hopeless because of fatalism. This is echoed in this study. Many of the participants, often as a result of anomalous family situations, had re-evaluated their beliefs and arrived at fatalistic explanations for cancer. There was widespread agreement that risk could not be eradicated but it could potentially be reduced by adopting healthier lifestyles.

11.4.3 Morality

This study adds to the body of work that demonstrates health is a profoundly moral construct. The studies included in Chapter 2, primarily those of Blaxter (1982) and Cornwell (1984), showed that inherent in discussions about health and causality were moral judgements. Both found that their participants were loath to attach culpability to individuals but also found that it was important to remain strong in response to disease. These studies were carried out at a time before the move to the 'prevention' model and the subsequent concentration on personal disease avoidance took hold (Davison, Frankel & Davey Smith 1992). This present study was conducted in a climate where personal responsibility for disease avoidance is an accepted cultural norm. Was this ideological shift evident in the interviews? Undoubtedly many of those interviewed were keen to demonstrate not only that they were aware of what constituted healthy choice but also that they made the right choices. This echoes earlier findings by Crawford (1984). By outlining their good behaviour they were inhabiting what they see as an appropriate moral position.

Many were reluctant to label 'cancer candidates' with the expectation of smokers, perhaps because they felt that it was morally unacceptable. Yet while explicit candidacy models were shied away from most participants had little difficulty separating good from bad behaviours, and sometimes implicit in these conversations was the moral status of those engaging in such behaviours. Sometimes the judgements were explicit. Often the idea of 'deserving' or more pertinently 'not deserving' cancer came up. This is recognisable as everyday cancer talk. In this study children were thought not to deserve cancer, and few could explain causality in children. The potential culpability of mothers was introduced, however. So although Clow (2001) rejected the strength of the stigma related to cancer some of the participants in this study made critical and quick judgements about culpability.

11.4.4 Smoking

Smoking had a special significance in this study. It was the most widely accepted cause of cancer, and smokers were clearly identified as candidates. However it was clear that the absolute risks of smoking depicted in health promotion

materials introduced questions in the minds of some participants. If some people can smoke and remain disease free, why not all? The difficulty of course is the certainty with which the message is portrayed, as Davison pointed out. Changing attitudes to smoking are evident throughout the interviews and, particularly in the affluent area, participants were eager to excuse the smoking of relatives or emphasise their 'trade-off' with good behaviours. Backett (1992a) similarly concluded that good and bad behaviours are balanced or off set to provide a holistic model of a healthy lifestyle. As well as smokers themselves, relatives of smokers were equally keen to make allowances for their loved ones and on a number of occasions deny the role of smoking in causality.

11.4.5 Age

Participants were asked to consider whether the cancer patients they knew had anything in common. Generally, they concluded that they did not but in reality what they often had in common was age. Many participants displayed an interesting attitude to cancer and age. Although many assumed that age was a risk factor for cancer, this was expressed as a commonsense view rather than knowledge gathered from 'expert' sources. Instead cancer was viewed almost as a by-product of ageing and it was not uncommon for participants to state that 'you have to die of something'. The typical narratives of tragedy and suffering did not apply to cancer in the elderly. Suffering was not thought to be as severe when the person is older and the disease is not likely to be as aggressive. Participants believed that this was because cells were thought to be 'healthier' in young people and therefore multiplied more quickly. The ageing process, characterised by the body slowing down, is also applied to biology. Indeed cancer was not viewed as quite the killer in the elderly. Nevertheless, despite the relative indifference towards cancer in the elderly, it was often thought unwise to inform older people of cancer diagnoses. This may be a hangover from the stigma once attached to cancer.

11.5 Chapter Summary

This chapter reflected on the study's original research questions and offered some additional reflections on other notable findings. The next, and final, chapter will summarise the main findings from the study and reach some

conclusions before going on to suggest how these findings might usefully be developed in a future research agenda.

12. Summary & Conclusions

The aim of this study was to explore the utility of the lay epidemiology model when reflecting on ordinary beliefs about cancer. Originally the concept was developed by Davison and colleagues using data from an ethnographic study carried out in South Wales in the late 1980s. The communities involved in the study had recently been subject to a series of health educating activities that sought to highlight the risk factors associated with coronary heart disease (CHD). What emerged from the ethnography was a clear recognition of a ‘coronary candidate’ that was, according to Davison, a cultural mechanism that allowed an estimation of CHD risk. Candidacy however was fallible and this was illustrated by the identification of both anomalous deaths and unwarranted survivals. In the face of uncertain aetiology participants in South Wales turned to fatalistic explanations like luck to account for irregular events. This rational and logical estimation of risk, it was suggested, might help explain the failure for the public to wholeheartedly embrace lifestyle change. Davison evoked Geoffrey Rose’s prevention paradox which questioned the wisdom of adopting a population strategy to health promotion. The approach, while yielding benefits at a population level, will mean little for the individual. Indeed, in changing the boundaries of risk the numbers thought to be high risk increased but CHD events continue to occur more frequently out with the high risk group. Consequently, the lay public observe increased numbers of both anomalous deaths and unwarranted survivals.

At its most fundamental, lay epidemiology describes a method of information gathering that incorporates evidence from wide sources. The immediate family, wider family, social networks, the general public, and the media all contribute to the development of an explanatory model of CHD. The same is true of cancer. Participants in this study arrived at an explanatory model of cancer by drawing together a varied set of narratives that gave them an individually tailored evidence base. A model that is ever-changing to incorporate new evidence is described.

Central to Davison’s notion of lay epidemiology was the ‘coronary candidate’ that allowed an estimation of risk. Candidacy could be applied prospectively,

but was more successful retrospectively. The examples Davison offers to illustrate coronary candidacy are powerful and are familiar evocations of everyday CHD talk. Cancer talk was equally familiar and discussed via a few typical narratives. These narratives are no less culturally embedded but the culture is dramatically different. The review of literature in this thesis has shown that CHD inhabits a unique cultural position. It is a disease that attracts little fear or dread in the public psyche and has been identified as representing a good, and crucially, quick death (Emslie, Hunt & Watt 2001a). Cancer is the antithesis of CHD. The findings from this study confirm the literature that has focused on the culture of cancer and shows that it is a disease commonly linked with uncertainty, tragedy and fear (Sontag 1978; Patterson 1987; Scanlon et al 2006). These cultural differences have significant implications for the applicability of lay epidemiology to cancer.

The dreaded nature of cancer meant that often participants in this study were reluctant to attach cancer candidacy labels. Smokers were the notable exceptions to this. Like physical stature in Davison's study, smoking status was the first factor to be offered as explanation and the only risk factor that acted as a possible predictor of future candidacy. Other than smoking, risk factors for cancer were not universally recognised. Coronary candidacy is successful because the risk factors for CHD are well understood by the lay public. The same is not true for cancer and so candidacy is bound to be undermined. Without clarity around risk factors the scope for observing anomalous deaths is broadened, and ultimately this challenges candidacy.

As well as being culturally different, cancer and CHD are very different diseases. The ease with which the lay public recognise the mechanistic biomedical origins of CHD was documented by Davison and others (Emslie, Hunt & Watt 2001a). Cancer is multisite and multi-causal. This study set out to establish whether the lay public thought of cancer as a homogenous disease. Cancer is talked about in generic terms, though site-specific details were provided in more in-depth narratives. Cancer though is looked upon as one disease that affects different parts of the body, rather than as an umbrella term for a group of diseases. Participants' interpretation did not capture the complexity of cancer. The lack of simplicity contributes to the weakness of cancer candidacy

It might be argued that such stark biomedical differences between cancer and CHD indicate that any attempt to explore lay epidemiology in the context of cancer, and especially generic cancer, was fruitless from the outset. While a study of lung cancer candidacy would undoubtedly have found clear links with smoking, any other cancer, taken in isolation might have had similar struggles. One of the few studies that took Davison's original model as its starting point considered lay epidemiology in the context of breast cancer, and concluded that a firm concept of breast cancer candidacy was equally illusive (Salant & Gehler 2008).

Davison supposed that the lay epidemiological method of arriving at risk, by utilising observed population data, tested health promotion. Others however have emphasised the differences between lay and mainstream epidemiology Hunt & Emslie (2001) proposed that events in the family will have most resonance and make more of a contribution to explanatory framework. They likened the information gathering and processing procedure to that of a qualitative researcher, who gains in-depth and more meaningful data. The findings from this study support both Davison and Hunt and Emslie's positions. Cancer is marked by tragedy and uncertainty. If such an event was apparent in a family, this was indeed central to the explanatory model. If, however, the only available data related to the cancer of an elderly relative - neither unexpected nor tragic - explanatory models were supplemented with distant anomalous and tragic cases. Tragic and unusual cases of cancer were more likely to be recalled and retold. So while the lay view of cancer may be formed by drawing on elements of epidemiology and qualitative research, they also utilise methods employed in the mass media. They tell stories that are worth telling. It should be stressed that the lack of certainty around risk factors for cancer, leaves plenty of space for tragedy and anomaly to emerge.

12.1 What does this study add?

This study adds to the scarce body of literature that considers lay views of cancer amongst the ordinary public. Dein (2004) highlighted that there was a dearth of such material in the UK. A more recent example by Scanlon et al (2006) that considered the cancer beliefs among the Irish population and the indigenous white population in the UK reports similar findings. In addition this

study augments the health beliefs literature and is unique in considering the applicability of lay epidemiology to cancer. It shows that cancer means something quite different to CHD and this difference suggests that the concept of candidacy is of limited use. However in arriving at that conclusion the study confirmed findings from other studies that show that risk factors for cancer, with the exception of smoking, are not universally recognised. This too challenges any notion of candidacy. Although Davison proposed that coronary candidacy posed problems for health educators, this study shows that the failure of candidacy is equally problematic for health promotion.

12.2 Future Research

As well as drawing on observation of known cases, candidacy models, for both CHD and cancer do encompass known risk factors. Although coronary candidacy was originally presented with negative undertones, and used to explain the shortcomings of health promotion, it may be beneficial to consider the potential of candidacy. As Davison outlined, lay beliefs incorporate scientific explanations for CHD and this study found that participants make clear links between smoking and cancer and indeed smokers were marked as the only cancer candidates. Despite Davison's criticism of the simplicity of health promotion, such straightforward messages therefore appear to be effective in establishing candidacy, though guaranteeing subsequent changes in behaviour is more challenging. It is possible that candidacy could be encouraged, particularly in areas where risk is poorly understood, for example in relation to the risks between alcohol and cancer. Arguably, introducing ideas of personal culpability and moral responsibility may prove problematic. It may be more helpful to focus on areas separate from behaviour or individual actions, and re-establishing age as a risk factor for cancer may be an area where candidacy could be positively utilised.

Candidacy has more recently been used in the context of access to health care (Dixon-Woods et al 2006). In a review of available evidence, the authors concluded that vulnerable groups often fail to see themselves as warrantable candidates for health care. The uptake of preventative care could be improved if candidacy was better established. Though Dixon-Woods explicitly states that this candidacy model is distinct from Davison's coronary candidate, there are

similarities in the concepts. Taken together the models may prove a useful tool for health educators. Davison's concept of coronary candidacy relied heavily on the cultural understanding of CHD and this study also showed the importance and strength of cancer's cultural resonance. There is a need to better understand the socio-cultural position of illness to better understand the perception of risk. A discussion of candidacy within high risk groups that focus on specific risk behaviours could form the basis of future health promotion activities. Obesity, for instance, is an area that might benefit from a greater understanding of risk perceptions which may in turn illuminate the reasons for the success or failure of interventions to tackle obesity. Arguably both models need further exploration, but there is scope to harness the notion of candidacy and use it to promote salutogenic behaviours.

Appendices

Appendix 1: Letter of Ethical Approval

Appendix 2: Community Organisations

Appendix 3: Volunteer Poster

Appendix 4: Letter to Community Groups

Appendix 5: Participant Information Sheet

Appendix 6: Consent Form

Appendix 7: Topic guide.

Appendix 8: Coding Frame

Appendix 9: Nvivo Node Report

Appendix 10: Proximity Vignettes

Appendix 1

Appendix 2 Community Organisations

New Kilpatrick Parish Church, Manse Rd, Bearsden	Milngavie & Bearsden Camera Club
Bearsden North Church, Thorn Rd, Bearsden	Antonine Probus Club
All Saints Scottish Episcopal Church, Drymen Rd, Bearsden	Probus Club of Allander
St Andrew's RC Church, Roman Rd, Bearsden	Bearsden Literary Society
Bearsden Baptist Church, Roman Rd, Bearsden	Milngavie Library Reading Group
St Serf's Scottish Episcopal Church, Shettleston Rd	Rotary Club of Allander
Sandyhills Parish Church, Ballieston Rd	Bearsden and Milngavie Philatelic Society
St Paul's Church , Shettleston Rd	Bearsden and Milngavie Ramblers
St Joseph's Church, Fullarton Ave	Bearsden East Community Council
Carmyle Church of Scotland, Carmyle Ave	Bearsden North Community Council
Bearsden Art Club	Bearsden West Community Council
Bearsden and Milngavie Bridge Club	Milngavie Community Council
Antonine Bridge Club	Local Councillors, Glasgow City Council
Allander Indoor Bowling Club	Local Councillors, East Dunbartonshire Council
Bearsden Bowling Club	East End Community Health Partnership
Milngavie Bowling Club	Milngavie Family History Society
Bearsden Chess Club	Kelvin Choir
Bearsden Choir	Milngavie Flower Club
Bearsden Flower Club	Bearsden Horticultural Society
Bearsden Golf Club	Milngavie Golf Club
Bearsden and Milngavie Local History Study Group	

Appendix 3: Volunteer Poster



Volunteers wanted

I am a postgraduate student and am asking for your help in a student project. Cancer is a common disease and many of us will know someone who has or who has had cancer. I am interested in hearing about the general public's views and beliefs about the disease how their life experience shapes these views.

Taking part will involve an interview with me at a time and place convenient to you. You do not have to answer any questions you are uncomfortable with and can ask to stop the interview at any time.

I would be extremely grateful if you agree to take part. If you are interested please contact me and we can talk a little more about the study.

Thank you for taking the time to read this

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Appendix 4: Letter to community groups

October 2007

Dear

I obtained your contact details from the East Dumbartonshire Council website/ East End Community Health Partnership and I am emailing you in your capacity as xxxx of the xxxxx.

I am undertaking my PhD at the University of Glasgow and want to talk to people about their views about cancer. I am looking to speak to people who have not had cancer themselves. I wonder if this is something your members may be interested in? If it would be helpful for me to come to speak to your group, please let me know and I will arrange to do that. I have attached a little more information but if you need anything further I'd be happy to discuss the study.

Thank you very much
Yours sincerely

Sara Macdonald
Research Fellow

Tel: 0141 330 8325

email: smd26h@clinmed.gla.ac.uk

Appendix 5 Participant Information Sheet



An exploration of lay beliefs about cancer

'You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.'

What is the purpose of the study?

The study is being carried out as a student project by the researcher Sara Macdonald. She is interested in what the general public think about cancer. In particular she would like to know what you believe causes cancer, who is at risk of getting cancer and if some people are more likely to get the disease than others. She is also interested in experiences that might have affected your views.

Why have I been chosen?

You have been chosen at random. The researcher visited a number of groups and clubs in your area.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason. The information from the interview will be used as part of a postgraduate student project. All the information is anonymous and no information will be identifiable to yourself.

What do I have to do?

We are asking you to take part in an interview with our researcher. She will ask you some questions about what you think about cancer, what you believe causes the disease and who is at risk. The interview will be taped if you agree to it. This is so we can remember what you have said.

What are the possible disadvantages and risks of taking part?

There are no disadvantages to taking part, other than the time it will take you to complete the interview. We estimate this to be about an hour. You will be able to stop the interview at any time, and ask us to destroy the tape.

What are the possible benefits of taking part?

You will receive no direct benefit from taking part in this study. The information collected during this study will help us to understand more about people's beliefs about cancer.

What will happen to the results of the research study?

The information collected during this study will be written up as a student project. We may also prepare it for publication in academic journals.

Who is organising and funding the research?

The study is being organised by Sara Macdonald as part of her postgraduate study. Sara is based in the Section of General Practice at the University of Glasgow.

Who has reviewed the study?

The project has been reviewed by the University of Glasgow Faculty of Medicine Ethics Committee.

Contact for Further Information

Further information can be obtained from:

Ms Sara Macdonald, Section of General Practice and Primary Care, Division of Community Based Sciences, University of Glasgow, 1 Horselethill Road Glasgow G12 9LX, telephone 0141 330 8330 or email: s.macdonald@clinmed.gla.ac.uk

Thank you very much for taking the time to read this information sheet

Appendix 6 Consent Form



CONSENT FORM

Study title: An exploration of lay beliefs about cancer

Name of Researcher: Sara Macdonald

Please initial box

1. I confirm that I have read and understand the information sheet for the study. . ☐
2. I understand that this interview will be audio-taped. Information from the diary and interviews will be treated with confidentiality and none of the information in my interview will be traceable back to me. ☐
3. I understand that all personal identifying data will held securely for a period of up to ten years. ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
5. I understand that data collected during the study will be used by researchers involved in the study and anonymised data may be archived and used in future research. ☐
6. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Researcher

Date

Signature

Appendix 7 Topic Guide

An exploration of lay epidemiology and cancer

*TOPIC GUIDE FOR INTERVIEWS WITH GROUP
MEMBERS*



Prompts:

Have you known many people who have or have had cancer?

Can you tell me a little about them?

Could you tell me what sort of cancer that is/was?

Were you surprised that they got cancer?

Do the people you know with cancer have anything in common?

What do you think are the main causes of cancer?

Could you tell me how much of at risk the average person is of cancer?

What about people who do all the right things and get cancer – can you explain that?

What about people who adopt unhealthy behaviours, like smoking but don't get cancer, can you explain that?

What about childhood cancer – can you explain that?

What about famous people?

Has the way you think about cancer changed over time?, If so, why might that be?

Appendix 8: Coding Frame

Coding frame: version 1

Explanations	Lay epidemiology	Risk	Narratives
Aetiology Smoking; Genetics Working conditions Environmental Clusters; Personality; Socio-economic inequality	Anomalous deaths	Personal risk Population risk	Cancer Journey
Healthy/Unhealthy lifestyle	Unwarranted survivors	Behaviours	Dealing with cancer
Disputed/questioned explanations	Candidacy Predictive/retrospective		
Myths			

Coding Frame _ Final Version

Explanations	Lay epidemiology	Risk	Meaning & understanding	Proximity (closeness of personal experience)	Individual Narratives
Layered aetiology Smoking; Genetics Working conditions Environmental Clusters; Personality; Socio-economic inequality	Anomalous deaths Disconfirming events Children	Personal risk Individual risk (people known to them) Family risk Community risk Population risk	Death Survival Fatalism Big C	Spouse Parent Inner circle Outer circle Celebrity	Dealing with cancer
Healthy/Unhealthy lifestyle	Unwarranted survivors	Behaviours good bad - moral judgements	Shifts in meaning time personal experience	Impact of proximity	Imagery/descriptions combative human trait
Disputed/questioned explanations	Candidacy Predictive/retrospective	Hierarchy of risk	Prevalence		Borrowed narratives
	Community Perspective - Affluence/Deprivation	Protective behaviours	Homogeneity - Family of conditions		
Triggers			Metaphors		
Randomness			Comparison with CHD		
Can science explain?					

Appendix 9 Nvivo Node Report

NVivo revision 2.0.163

Licensee: Sara Macdonald

Project: PhD User: Administrator Date: 26/11/2010 - 14:28:43

NODE LISTING

Nodes in Set: All Tree Nodes

Created: 27/05/2008 - 13:31:03

Modified: 27/05/2008 - 13:31:03

Number of Nodes: 132

- 1 (1) /explanations
- 2 (1 1) /explanations/smoking
- 3 (1 1 1) /explanations/smoking/passive smoking
- 4 (1 2) /explanations/other behavioural
- 5 (1 2 1) /explanations/other behavioural/alcohol
- 6 (1 2 2) /explanations/other behavioural/sun
- 7 (1 2 3) /explanations/other behavioural/stress
- 8 (1 2 7) /explanations/other behavioural/obesity~diet
- 9 (1 2 9) /explanations/other behavioural/personality
- 10 (1 3) /explanations/environmental
- 11 (1 3 2) /explanations/environmental/work hazards
- 12 (1 3 4) /explanations/environmental/pollution
- 13 (1 3 8) /explanations/environmental/food additives
- 14 (1 3 16) /explanations/environmental/mobile phones
- 15 (1 3 18) /explanations/environmental/electricity pylons
- 16 (1 4) /explanations/biological
- 17 (1 4 3) /explanations/biological/genetics
- 18 (1 4 3 4) /explanations/biological/genetics/ticking time bomb
- 19 (1 4 6) /explanations/biological/hormones
- 20 (1 5) /explanations/familial
- 21 (1 6) /explanations/secondary event
- 22 (1 7) /explanations/moral position
- 23 (1 8) /explanations/psychology
- 24 (1 9) /explanations/need for explantion
- 25 (1 10) /explanations/lifestyle
- 26 (1 11) /explanations/link b~w cause & site
- 27 (1 12) /explanations/all cause
- 28 (1 13) /explanations/we all have it
- 29 (1 13 1) /explanations/we all have it/trigger
- 30 (1 13 16) /explanations/we all have it/triggered
- 31 (1 17) /explanations/luck~random
- 32 (1 19) /explanations/explanatory model
- 33 (1 30) /explanations/age
- 34 (2) /meaning & understanding
- 35 (2 1) /meaning & understanding/unpredictable
- 36 (2 1 2) /meaning & understanding/unpredictable/you never know ~
- 37 (2 1 6) /meaning & understanding/unpredictable/asymptomatic
- 38 (2 2) /meaning & understanding/positive
- 39 (2 2 4) /meaning & understanding/positive/benefit of catching it early
- 40 (2 2 5) /meaning & understanding/positive/curable
- 41 (2 2 15) /meaning & understanding/positive/survival
- 42 (2 3) /meaning & understanding/comparison with TB
- 43 (2 4) /meaning & understanding/screening
- 44 (2 6) /meaning & understanding/tragedy
- 45 (2 13) /meaning & understanding/its common
- 46 (2 14) /meaning & understanding/relative danger of site
- 47 (2 16) /meaning & understanding/The Big C
- 48 (2 16 1) /meaning & understanding/The Big C/spread
- 49 (2 16 2) /meaning & understanding/The Big C/aggressive
- 50 (2 16 3) /meaning & understanding/The Big C/its too late

51	(2 16 6) /meaning & understanding/The Big C/cancer = death
52	(2 16 7) /meaning & understanding/The Big C/fear
53	(2 16 8) /meaning & understanding/The Big C/pain
54	(2 16 9) /meaning & understanding/The Big C/horrible death
55	(2 16 10) /meaning & understanding/The Big C/wasting away
56	(2 17) /meaning & understanding/what is cancer like~
57	(2 17 1) /meaning & understanding/what is cancer like~/images
58	(2 17 20) /meaning & understanding/what is cancer like~/analogies
59	(2 17 20 1) /meaning & understanding/what is cancer like~/analogies/combatative language
60	(2 34) /meaning & understanding/clusters
61	(2 35) /meaning & understanding/childhood cancer
62	(2 36) /meaning & understanding/comparison with CHD
63	(5) /attitude to NHS
64	(7) /knowledge
65	(7 1) /knowledge/weaving lay~expert descriptions
66	(7 2) /knowledge/sources of information
67	(7 13) /knowledge/not expert
68	(7 37) /knowledge/media
69	(9) /Risk
70	(9 1) /Risk/personal risk
71	(9 2) /Risk/experienced already
72	(9 3) /Risk/can't eliminate risk
73	(9 4) /Risk/candidacy
74	(9 5) /Risk/annomolous case
75	(9 6) /Risk/unwarranted survivor
76	(9 7) /Risk/population view
77	(9 23) /Risk/it won't happen to me
78	(10) /behaviours
79	(10 1) /behaviours/'bad'
80	(10 1 6) /behaviours/'bad'/ignores advice
81	(10 2) /behaviours/'good behaviours'
82	(10 3) /behaviours/personal accounts
83	(10 4) /behaviours/others
84	(10 5) /behaviours/moderation
85	(10 6) /behaviours/hypochondriacs
86	(10 27) /behaviours/upbringing
87	(11) /experience of cancer
88	(11 1) /experience of cancer/delay
89	(11 2) /experience of cancer/impact of cancer
90	(11 3) /experience of cancer/individual cases
91	(11 3 1) /experience of cancer/individual cases/siblings
92	(11 3 2) /experience of cancer/individual cases/extended family
93	(11 3 3) /experience of cancer/individual cases/spouse~partner
94	(11 3 4) /experience of cancer/individual cases/friends
95	(11 3 5) /experience of cancer/individual cases/acquaintances
96	(11 3 6) /experience of cancer/individual cases/parents~in-laws
97	(11 3 7) /experience of cancer/individual cases/proximity
98	(11 3 8) /experience of cancer/individual cases/narrative
99	(11 3 9) /experience of cancer/individual cases/age of sufferer
100	(11 3 28) /experience of cancer/individual cases/celebrity 2
101	(11 4) /experience of cancer/recurrence
102	(11 5) /experience of cancer/dealing with disease
103	(11 6) /experience of cancer/perception shift
104	(11 6 1) /experience of cancer/perception shift/time
105	(11 6 2) /experience of cancer/perception shift/experience
106	(11 8) /experience of cancer/professionals
107	(11 9) /experience of cancer/symptoms
108	(11 9 4) /experience of cancer/symptoms/fear the worst
109	(11 10) /experience of cancer/speed
110	(11 28) /experience of cancer/cancer sites
111	(11 31) /experience of cancer/shock
112	(11 38) /experience of cancer/was it cancer~
113	(12) /aesthetics of 'health'

114	(14) /positive stories
115	(15) /science
116	(15 1) /science/research
117	(15 2) /science/does science know~
118	(15 17) /science/contradictory evidence
119	(15 20) /science/medical advances
120	(16) /health education
121	(18) /affects everyone
122	(25) /deprivation~affluence
123	(25 1) /deprivation~affluence/bearsden
124	(25 26) /deprivation~affluence/poor get everything
125	(26) /healthy living
126	(26 1) /healthy living/happiness~contentment
127	(26 22) /healthy living/positive attitude
128	(26 24) /healthy living/do the right things
129	(26 33) /healthy living/attitude to life
130	(29) /parent's health
131	(32) /fatalism
132	(39) /community

Appendix 10 Proximity Vignettes

Affluent Participants

The first interviewee was Lisa, (45) year old professional. Lisa's husband had been diagnosed with colorectal cancer two years previously. He had recovered well despite a long diagnostic delay. He had experienced a recurrence but that too was successfully managed. Just months before her husband's illness, her mother-in-law had been diagnosed with and, died very quickly of lung cancer. She was a non-smoker. It was this event that prompted her rethink of what she thought she knew about cancer, and this need was only emphasised following her husband's diagnosis. Her only previous experience of cancer had been amongst elderly relatives or her wider social network, and neither her mother-in-law nor husband fitted her preconceived cancer profile. Lisa was extremely thoughtful during the interview but she remained angry at the lengthy diagnostic delay. This was the first time she had discussed her story outside of her family and friends and admitted that she enjoyed the process.

Engaging with Murray (83) was quite different. He began by stating that he had no close experience of cancer. He was adamant that tobacco was the main and possibly only carcinogen worth discussing. He was wedded to scientific explanations and was reluctant to engage in speculation on any level. If he didn't know the 'facts' he was not prepared to comment. Later he went on to admit that both his parents had smoked and that upon his mother's post-mortem at the age of 92, a lung cancer "that would never of killed her" was discovered.

Kathleen (68) decided to take part in the study because she had an interest in health things. She had experience of a number of family members, mostly aunts and uncles who had died of cancer when she was in her 20s and 30s. Her father, she believed had died of 'some form of cancer' but that, she admitted, had never been confirmed. Her closest friend was, on the day of the interview, receiving surgery for colorectal cancer. Kathleen was extremely calm and described how she had sought out information, primarily from the internet, on her friend's behalf. She was very well-informed, though she was not pessimistic.

Andrew (57) knew little about cancer. He had no 'close' experience of cancer, though he was aware that his sister-in-law had cancer. The site had to be confirmed from a discussion with his wife, who he looked to often for information. His wife did not participate in the interview. He had no awareness of risk factors beyond smoking and he admitted that only recently had he become aware of the many different cancer sites. This was precipitated by the diagnosis of oral cancer in a close friend and he had previously not known it possible to get oral cancer.

Jessie's (63) motivation for participating in the interview was, like Murray's, a sense of duty. She is interested in cancer and as a retired nurse who volunteers in a hospice had much to say about cancer generally. Her mother had died of gastric cancer in her 80s and she had been her main carer. The fear and stigma surrounding cancer was evident throughout Jessie's interview. She had never

disclosed her mother's diagnosis to her and had removed mirrors from her house in order that her mother did not witness her demise.

Both Elsie's (62) mother and husband had cancer, and though her mother died, her husband had recently received the 'all-clear'. She attributed his head and neck cancer to his work as an illustrator and had arrived at this conclusion because she had seen a documentary about the carcinogenic properties of paint. She was hesitant about the role of her husband's smoking in his cancer. Often she said that she didn't like to think about cancer and that she had simply decided 'that's not for me'. On hearing of her husband's diagnosis she said she decided that they would 'act like he had flu' but simultaneously she began observing his everyday household chores in order that she could undertake such tasks 'if need's be'.

Jim (64) and Phyllis (58), a married couple, were interviewed together. Jim had little experience of cancer but Phyllis' mother had survived cancer three times. A close friend had recently died of colorectal cancer and this was regarded as an anomalous death. She was asymptomatic and had died very quickly. They had settled on passive smoking as the root of her cancer because of her work in a bar. They also attributed Phyllis's mother's cancer to smoking but knew of many people who had smoked and remained healthy into older age. Jim in particular was moralistic about disease. His sister, who was 18, had died when he was a teenager and he questioned why drug addicts manage to remain disease free.

Colin (61) had a limited experience of cancer. His first experience was that of his grandfather, who died when he was 14 and this had remained with him. His brother recently died suddenly of pancreatic cancer. The cancer was diagnosed following an emergency admission to hospital. As they were not in touch he found out afterwards and had no knowledge of his brother's illness experience. He was sure that his brother would have ignored symptoms and wondered what would have happened had he gone to his GP early. Colin had a close friend who had been diagnosed with leukaemia more than 20 years before and had defied the odds.

Janet (46) was a nurse and had previously worked in neurology. She had experience of nursing patients with primary brain tumours and attributed these to smoking. Her grandmother had died of breast cancer, as had a close school friend. She didn't question why either of these events had happened, she simply assumed that breast cancer was common. The cancer event that had most impact on her was that of her aunt, who had died of oral cancer. Her aunt was healthy; the diagnosis 'came out of the blue' and she died very quickly. Janet described this as especially tragic because her uncle committed suicide soon after her aunt's death.

Grace's (62) husband had died of colorectal cancer seven years before the interview. He was first diagnosed 10 years before that, though Grace was clear that he had ignored his symptoms for many months. She had been his main carer and because he died many years post-diagnosis, she described the illness as long and drawn out. She assumed that her husband's cancer was caused by smoking. Her brother died of asbestosis.

Angus (56) was the only participant to use the word candidate in relation to cancer. He described his older brother, who had died of pancreatic cancer as an 'ideal candidate' because of his unhealthy lifestyle. His brother had died very quickly - three days after first presenting to his GP. Angus was one of four brothers and weeks before the interview another brother had been diagnosed with mantle-cell carcinoma. Despite a poor prognosis, Angus was sure that they would be able to 'beat' his brother's disease. Angus interpreted risk statistics quite literally and so believed that from his family group of four brothers, two had cancer, so he was likely to avoid it.

Emily (37) was an allied health professional. Both her parents-in-law had cancer. Her mother-in-law died in her early 50's, but her father-in-law was now cancer free in spite of an initially poor prognosis. Both had smoked so 'they knew the risks'. Although she was keen to down-play the genetic links in cancer, it was clear that she was concerned for her husband and children. Her husband had originally agreed to take part but eventually declined. He found it a difficult area to talk about. Emily had changed her view of cancer because her uncle (her maternal aunt's husband) had died of throat cancer and met none of the risk criteria.

Clare (42), in the four years before the interview had lost her mother, father and best friend to cancer. Her grandmother had also died of uterine cancer. With the exception of her father, who had worked with chemicals, she could not explain any of these events. She was extremely candid about her mother's psychological health which she had settled on as the only possible risk factor. Her experience had led her to conclude that cancer was simply random and little could be done to avoid it.

Jenny (38) was also an allied health professional. She chose to meet in her place of work and refused permission to record the interview. Although she said she had known people with cancer, she would not disclose the level of relationship. Any insight she offered was from a purely professional perspective.

Both Barbara's (64) parents had died of cancer but because they were elderly she had somehow discounted it as cancer. It was not her parent's cancers that she offered most narrative about. Rather she fixed on the case of a work colleague who had died of breast cancer in her 30s. It was this experience that had formed Barbara's view of cancer and had been completely unexpected and very much an anomalous case. Barbara's main reason for judging this as anomalous was that her colleague was 'meticulous', 'precise' and she didn't think such people got cancer.

Eileen and Barry, also a married couple opted to be interviewed separately. Eileen had a number of cases to draw on - her brother, her sister-in-law, others in her social network. All of these people, as far as she was aware had led 'healthy, good lives', with the exception of her brother. He had, what she described as, a chequered past, which could explain his cancer. She was not uncomfortable talking about this and ended the interview fairly quickly. Barry (74) confirmed the cases that Eileen had introduced but was less clear that his brother-in-law was responsible for his cancer because of his behaviour. Barry also knew of a number of men within his social circle that had prostate cancer.

He was sure that age was a risk factor and thought that everyone old 'had some kind of cancer'. His knowledge of other risk factors was reasonably poor though he supposed that diet and exercise were important.

Deprived participants

Both Betty's (61) mother and mother-in-law had cancer and she had been their main carer. Her mother had gastric cancer and had experienced a long pre-diagnostic delay and then a fairly quick death. It was a difficult time and very painful for Betty. She blamed her mother's smoking for her cancer, and she smoked up until she died aged 70. Her mother-in-law was 83 when she died and she had also died very quickly following her diagnosis. Betty said that her mother-in-law was terrified of cancer and felt it better not to disclose her diagnosis. This experience had not been as traumatic as her mother's. Betty was also aware of many other cancer stories from her family - including her brother who had been diagnosed with throat cancer but was a non-smoker - and her wider social network.

Charles' wife (74) was undergoing treatment for endometrial cancer at the time of the interview. Her prognosis was good and was at the mid-point of her chemotherapy treatment. He also had many friends who had had cancer and could not arrive at an explanation, apart from smoking. His wife's diagnosis was so recent that he hadn't considered why she might have had cancer. She was a non-smoker.

Gary (37) and Caroline (37), a married couple chose to be interviewed together. Caroline then offered little. Initially they thought they knew few people with cancer though Gary's father had survived prostate cancer 12 years before. Gary talked about his father as an unwarranted survivor. As the interview progressed they remembered many more neighbours, friends, and school friends who had all died of cancer. Gary talked about his cousin who had died of breast cancer. She had had a difficult home life and had 'given up' following the diagnosis. He believed that if she hadn't had such an attitude she may have survived.

Karen (25) was the youngest participant and had very little experience of cancer. Her uncle had died of gastric cancer when she was a child but knew few of the details because of her age. He was in his 30s. She also had a school-friend who had died of cancer - though she was not clear of the site and said that she had been attending the doctor because she had a sore leg. Her friend died aged 19.

Patricia (62) had many examples of cancer from family and friends on which to draw. Both her parents had died of cancer and both were in their 70s. Although both her parents smoked and had lung cancer she had searched for other explanations. Her father was violent and her mother the victim of domestic abuse, and she thought this had contributed to her mother's cancer. She believed that ultimately her mother's cancer had been triggered by a mugging, which had shaken her and a few weeks later she received a diagnosis of cancer. Patricia was privy to information from an elaborate social circle and despite the presence of risk factors in sufferers' behaviour Patricia saw all these cancer deaths as anomalous.

Pauline's (57) mother was present during the interview but remained silent almost throughout. Near the end of the interview she simply said 'my granny Jessie said, if you fear it you'll get it'. Pauline began the interview by saying that she felt lucky that cancer was not in her family but then went on to offer narratives of a paternal aunt and then uncle who had both died of cancer. Pauline's close friend was from a cancer family, where parents and many siblings had cancer. Her friend was fearful that she would be unable to escape cancer, and she had recently been diagnosed with melanoma, thus confirming Pauline's belief that cancer is apparent in families.

Rose's (61) first experience of cancer was that of a maternal aunt that had died of breast cancer, leaving a young family. Her memory was of her mother caring for her aunt and nursing her at home. Beyond her aunt, she could remember a neighbour of her mother's who also had breast cancer and also left a young family. Rose also believed that illnesses 'ran' in families and in her family they had problems with cholesterol.

Josephine (61) had a number of close experiences of cancer. Both her parents-in-law had died of colorectal cancer and she was surprised that her husband had not because of the familial link. Her friend's husband had recently died 'quickly' of oesophageal cancer and another friend who they assumed had come through colorectal cancer had just discovered that she had a recurrence. Josephine was continually struck by the unpredictable nature of cancer and was aware of many narratives that provided evidence of this.

Lorna (57) had many cases of cancer 'in her family' and was one of the few participants who knew a child that had died of leukaemia. All these different cancers, among these different people had led Lorna to conclude that cancer is in all of us and requires a trigger.

Rona (31), Peter (67) and Julia (65) were all members of one family and chose to be interviewed individually. It was interesting hearing about the same cancer stories but from three different perspectives. Julia's sister had died recently of oesophageal cancer and this had been traumatic for the family but Julia, in particular. At the time of diagnosis, alcohol was identified as a risk factor but Julia was adamant that her sister was a moderate drinker. Julia's father had also died of a brain tumour that had gone undiagnosed for some time. Julia had clearly been searching for causal explanations and had eventually arrived at the idea of dormant genes. Both Julia and Peter used the same gardening metaphor to describe cancer. Peter's mother was thought to have died of cancer but that was never confirmed.

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